

PATIENT AND PROFESSIONAL PERSPECTIVES ON LIVING WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE

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Patient and Professional Perspectives on Living with Chronic Obstructive Pulmonary Disease

Abstract

The aims of this study were to explore the lived experience of people with COPD and the views of healthcare professionals involved in the care of patients with COPD. The research question asked how health providers are meeting the psychosocial needs of people with COPD. Recent literature suggests that some patients with COPD are leaving primary care consultations with unmet psychosocial needs and that healthcare providers report being unwilling to promote behaviour change as they perceive it could damage their ongoing relationships with their patients. Data were collected from semi-structured interviews carried out with nine people with COPD and ten healthcare professionals (HCPs). The interviews were transcribed verbatim and the data analysed using Attride-Stirling's (2001) model of thematic network analysis. Examples of themes deduced from the findings of the COPD group were loss and lifespan health. Those from the HCP group included attitudes and patient care. Both groups yielded a global theme of individuality. Findings from the study suggest that COPD patients are happy with their experience of healthcare although they valued prompt, accessible care in an emergency more highly than routine review appointments. They did not indicate that their psychosocial needs were met in routine consultations although they reported that some of these needs were met during pulmonary rehabilitation. HCPs perceived that they provided good care but that there were barriers to introducing psychosocial issues into routine appointments. In a time of change in patient demographics resulting in an increased number of older people with long-term conditions, this study adds to the body of knowledge in this field by exploring the lived experience of both people with COPD and of HCPs. The global theme of individuality for each group supports the need for person-centred care in the healthcare system in order to meet individuals' psychosocial needs. Recommendations include; increased provision of pulmonary rehabilitation courses and training for HCPs in order for them to be more aware of the psychosocial needs of patients attending routine appointments.

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CHAPTER 1 - INTRODUCTION

Patient and professional perspectives on living with Chronic Obstructive Pulmonary Disease (COPD)

Research Question:

The lived experience of people with chronic obstructive pulmonary disease (COPD):
How are health providers meeting their psychosocial needs?

Aims of the study:

In the light of the existing evidence, literature around the care of people with COPD and the need to establish a system of care to meet their needs, this study aims to:

- a) Explore the lived experience of people with COPD
- b) Explore the views of healthcare professionals involved in the care and treatment of patients with COPD

Objectives of the study:

1. To establish the extent to which the physical and emotional symptoms experienced by individuals with COPD affect their quality of life and ability to carry out their day-to-day activities.
2. To understand how the experiences of clinicians in treating people with COPD are related to the perceived needs expressed by the patients.

1.1 Background to the study

This chapter will begin by outlining my personal, employment and academic background and the reasons for embarking on this research project. It will continue by describing the impact of COPD, as a condition affecting a large number of,

predominantly older, people and will then explain in more detail how COPD is defined and diagnosed.

In order to obtain a sound understanding of the challenges faced by people living with COPD, the next section of the chapter will look at the most common symptoms of the condition and the treatments offered for them. As the research question for the study is concerned with the psychosocial needs of individuals with COPD, particular attention will be paid in this introduction to the presence of psychological comorbidities and how anxiety interacts with the symptoms of COPD, especially with breathlessness.

The penultimate section of the chapter will be concerned with a perceived requirement for change in the healthcare system in order to meet the needs of a changing patient demographic. Finally, this chapter will conclude by considering the importance of exploring the lived experience of patients themselves, in order to help to develop systems and interventions to provide the most appropriate and efficacious healthcare for this patient group.

1.1.1.1. Personal Background

The original idea for this study was conceived during my time working as a receptionist and administrator in a large GP practice in a middle-class, suburban area in the North West of England from 1990 to 2010. During this period of employment, I was aware of some significant changes taking place in general practice. I perceived that the patient demographic was changing and that, increasingly, older people, with one or more long-term conditions, were attending the surgery on a regular basis. This change is described by Barnett et al. (2012) who explained how the presence of multimorbidity i.e. *“the co-existence of two or more chronic conditions, where one is not necessarily more central than the others”* (Boyd & Fortin, 2010, p.451), increases substantially with age and how it is now present in the majority of people over sixty-five years of age.

As a result, adaptations in the structure of the care provided by the GP surgery were necessary in order to meet these changing patient needs. Arguably, the most significant development came about when the Quality and Outcomes Framework (QOF, Department of Health, 2003) was introduced into GP practices in 2004 and GPs were incentivized to achieve measurable targets in the care of people with chronic diseases. This affected the care of those with long-term conditions, such as COPD or diabetes, who receive the large proportion of their care in the primary care setting. This resulting emphasis on routine care meant that people with chronic illnesses were invited to attend regular review appointments, usually with a practice nurse, in order to have their condition monitored.

During this period of employment, I also studied part-time, for a degree in Psychology at Manchester Metropolitan University. I followed this with a Masters degree by research, in which I explored the relationship between cognitive-perceptual factors of personality and memory performance. On completion of the Masters degree, I began a period of work as a senior research assistant for Manchester Mental Health and Social Care Trust, on a large National Institute for Health Research (NIHR) funded research project. This study was exploring the psychosocial factors that influence patients with long-term conditions in their decisions to use emergency care. Although, initially, I was employed to work mainly on the quantitative, questionnaire part of the research programme, there was a considerable amount of patient and public involvement and this gave me many opportunities to meet with participants and stakeholders. In addition to presenting the study and its findings at regular stakeholder meetings, I was also able to take part in group sessions and workshops with people who lived with one or more of the following four long-term conditions: coronary heart disease (CHD), asthma, diabetes and COPD. By listening to their narratives, I was able to learn about their experiences of care. This face-to-face contact with stakeholders, including representatives from relevant support groups, was instrumental in my desire to carry out my own research. I later became involved in the qualitative arm of the study and felt that, if I wanted to explore people's lived experiences, qualitative methods would be the most appropriate for this purpose. One of the findings that emerged from the qualitative arm of this study was that

some patients with long-term conditions felt unable to raise questions about psychosocial problems in routine consultations (Chew-Graham et al., 2013). This was something I found to be of particular interest in terms of whether healthcare professionals were meeting the needs of patients with long-term conditions.

When my contract with the research programme ended, I was fortunate enough to be given the opportunity to continue to carry out research, in the field of people's experience of long-term conditions, as part of a period of study towards a PhD qualification at Manchester Metropolitan University (MMU). I chose to concentrate my doctoral research on people with COPD, as, despite being such a prevalent condition, it has not been prioritised in the healthcare system, to the same extent as cancer and heart disease (Barnett, 2005). In addition, COPD, in elderly people, has been shown to have a higher rate of anxiety (36%) and depression (40%) associated with it, when compared with the general public (Yohannes et al., 2006). In their review of the literature, Gardiner et al. (2010) described how the need for information and open communication with health professionals was unmet in COPD patients. They also describe how people with COPD often suffer social isolation or anxiety, panic and depression because of their physical limitations but receive very little support in terms of specialist nursing, palliative care or social support (Gardiner et al., 2010).

In addition, I found that the literature around the effects of comorbid psychological conditions in COPD patients has indicated that depression and anxiety are important factors in people's lived experience of long-term illness. It has been shown that they are associated with functional impairment (Eisner et al., 2010), increased frequency of hospitalisation for exacerbations of COPD (Yohannes et al., 2000) and decreased quality of life (Cully et al., 2006). In addition, DiNicola et al., (2013) found that social support for people with COPD and anxiety had both positive and negative influences on the health of those concerned according to the type and consistency of support available. In the light of the existing literature, I perceived that the psychosocial needs of COPD patients and how these are addressed in the present healthcare system was an important topic for research. My intention in carrying out the research was to explore both the lived experience of people with COPD and the experiences

of healthcare professionals who worked with them, with particular reference to how patients themselves, and healthcare professionals, deal with the psychosocial needs of this patient group. In order to clarify in more detail why the research question for this study is relevant to the situation regarding the incidence, symptoms and treatment of COPD at the present time, the following section of this chapter explains the medical and social context in which this study takes place.

1.1.2 COPD – the present situation

Chronic Obstructive Pulmonary Disease (COPD) is a common, preventable and treatable disease, which is characterised by persistent airflow limitation that is usually progressive and associated with an enhanced chronic inflammatory response in the airways and the lung to noxious particles or gases. Exacerbations and comorbidities contribute to the overall severity in individual patients (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2014). It may also be defined, more simply, as a chronic, slowly progressive disorder characterized by airflow obstruction, which does not change markedly over several months (Bourke & Burns, 2011).

It is estimated by the World Health Organization (WHO) that 65 million people have moderate to severe COPD and that in 2005 more than 3 million people died of this disease, corresponding to 5% of all deaths worldwide (WHO, 2014). Almost 90% of deaths from COPD occur in low or middle-income countries. The condition now affects men and women almost equally due to increased smoking in women in high-income countries and an increase in indoor air pollution, for example from using biomass fuels for cooking and heating, in low-income countries (WHO, 2014). According to the WHO, COPD was the fifth leading cause of death in 2002 and projections suggest that this will increase by 30% in the next ten years unless risk factors, especially tobacco use, are reduced (WHO, 2014). Mathers & Lancar (2006) estimated that COPD would be the fourth leading cause of death by 2030 although a more recent estimate by the WHO (2014) predicts that it may be the third leading cause of death worldwide by 2030.

Measurements and projected estimates of the prevalence, morbidity and mortality of COPD worldwide are difficult to obtain accurately for several reasons. Most of the available information comes from high-income countries but, even there, accurate data on COPD are difficult and expensive to obtain (WHO, 2014). For example, Lopez et al (2006) report that death registration systems vary across countries and there can be problems with miscoding of COPD. In addition, some prevalence figures are based on self-reported symptoms, which may lead to an over estimation due to the inclusion of other respiratory diseases (Lopez et al., 2006). In England and Wales 900,000 people have a diagnosis of COPD, but it is estimated that the true figure could be up to 3 million, allowing for under-diagnosis (Healthcare Commission, 2006).

Patients' quality of life is a significant consideration for health services. People who have COPD also frequently have comorbidities. For example, population based evidence has shown that the prevalence of cardiovascular disease and the incidence of hospital admission for major cardiovascular events is higher in people with COPD than in the general population (Curkendall et al., 2006). The rate of bone problems such as fractures and osteoporosis, possibly due to steroid medication, and smoking related problems such as pneumonia and lung cancer, is also higher in COPD patients (Soriano et al., 2005). In addition, there is a higher incidence of psychological disorders, particularly anxiety and depression in people with COPD, than in the general public (Vogele and Leupoldt, 2007). The diagnosis and treatment of comorbid psychological conditions are important in meeting the psychosocial needs of COPD patients and are discussed in more detail later in the thesis.

Respiratory disease, COPD in particular, is estimated to cost business in England 24 million working days in sick leave and £3.8 billion from lost productivity (British Thoracic Society, 2006). In addition, the financial burden of COPD on the NHS is considerable with the cost of hospitalization due to exacerbations forming the major part of these costs (Chapman et al., 2006). Other costs include pharmacological treatments, treatments of complications associated with chronic COPD (i.e. cardiovascular disease) not withstanding primary and secondary prevention and maintenance costs in community settings.

In order to understand the lived experience of people with COPD it is necessary to have at least a rudimentary understanding of the disease itself, its diagnosis, symptoms, progression and treatment. Therefore, the next section of this introduction provides a brief outline of COPD to serve as a background to the present study.

1.2 Definition of Chronic Obstructive Pulmonary Disease (COPD)

As described earlier in this chapter, COPD is defined as a chronic, slowly progressive disorder characterized by irreversible airflow obstruction, which does not change markedly over several months (Bourke & Burns, 2011). This is often regarded as a combination of chronic bronchitis and emphysema. Although the two may co-exist, the relative contribution of each of these conditions varies between individuals (Rabe et al., 2007). In terms of the diagnoses of the two conditions, chronic bronchitis has a clinical definition and is characterised by the production of excessive amounts of mucus. However, the enlargement of the air spaces and parenchymal destruction characteristic of emphysema becomes apparent on histological examination of the lung tissue and is therefore difficult to diagnose accurately during a patient's lifetime (West, 2008). The airways of people with COPD are therefore obstructed because they are partially blocked by secretions (primarily due to chronic bronchitis), have experienced an increase in size of mucous glands and inflammation of the bronchial walls, which reduce the size of the airways (also due to chronic bronchitis) or have undergone destruction of the alveoli and the small terminal airways (due to emphysema) (West, 2008, Decramer et al., 2012). The consequences of these changes result in increasing breathlessness (dyspnoea) over several years, chronic cough, poor exercise tolerance, evidence of airways obstruction (confirmed by lung function tests using spirometry), hyper inflated lungs and poor gas exchange as the main features of COPD (West, 2008). Diagnosis of COPD is therefore based on examination of symptoms, relevant history of smoking and/or industrial exposure and spirometric measurements of lung function (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2014).

1.2.1 Chronic bronchitis

The criteria for a diagnosis of chronic bronchitis is *“expectoration (of sputum) on most days for at least 3 months in the year for at least 2 successive years”* (West, 2008, p.56). Repeated exposure, over a long period of time, to an inhaled irritant (usually cigarette smoke) causes chronic inflammation in the airways and enlargement of the mucous glands in the large bronchi resulting in excessive expectoration of mucus (West, 2008). Cigarette smoke has four main constituents, gases (mainly carbon monoxide), nicotine, irritants and carcinogens. It is the irritant constituent that is most important in the development of chronic bronchitis as the increase in mucus production and cough are normal protective reactions to an irritant (Sterling, 1983).

1.2.2 Emphysema

“Emphysema is characterized by enlargement of the air spaces distal to the terminal bronchiole, with destruction of their walls” (West, 2008). The destruction of the lung parenchyma in emphysema can be detected using high-resolution computed tomography (HRCT) scans, although, in practice it is usually diagnosed by clinical picture and lung function tests. There are two main types of emphysema: centriacinar, which involves damage to the respiratory bronchioles, characteristically affecting the upper lobes of the lungs, and panacinar, which results in distension and destruction of the whole of the acinus and particularly affects the lower half of the lungs (Bourke & Burns, 2011). As is the case with chronic bronchitis, both types of emphysema are related to smoking but may arise from different mechanisms (Bourke & Burns, 2011). The following section of the chapter will consider how COPD is diagnosed in the present healthcare system.

1.3 Diagnosis of COPD

Although the disease may begin to show when an individual is as young as twenty or thirty years of age, with a cough and production of a small amount of mucus, which is likely to be more prevalent following a cold, this is often dismissed by the patient as a “smoker’s cough”. As the individual gets older, a reduction in exercise tolerance may be regarded as “ageing” and it is usually only when frequent attacks of bronchitis, accompanied by breathlessness, begin to affect daily living and employment that help is sought (Cole & Mackay, 1990). As there is no single test that can be used to diagnose COPD, the diagnosis is made by relying on clinical judgement and a combination of history, physical examination and the use of spirometry to confirm the presence of airflow obstruction (Bourke & Burns, 2011).

Lung function tests are performed by clinicians using a spirometer, to diagnose, and monitor the progress of, COPD. The measurement of forced expiratory volume in one second (FEV1) and forced vital capacity (FVC) can distinguish between normal lung function (FEV1 is around 80% of FVC) and obstructive airways disease. The severity of COPD can be categorized into four stages, which are based on criteria set out by the Global Initiative for Chronic Obstructive Lung Disease (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2014). This staging gives an indication of the most appropriate form of treatment for the patient.

Table 1.1 - Stages of COPD – based on the GOLD criteria

STAGE		SYMPTOMS	FEV1
1	MILD	Minimal shortness of breath with or without cough/sputum. Usually not recognized at this stage that lung function is abnormal.	Greater than or equal to 80% of predicted FEV1/FVC > 0.7
2	MODERATE	Often moderate or severe Shortness of Breath on Exercise (SOBOE) with or without cough, sputum or dyspnoea. Often the first stage at which medical attention is sought due to chronic respiratory symptoms or exacerbations.	50 to 80% of predicted FEV1/FVC < 0.7
3	SEVERE	More severe SOB with or without cough, sputum or dyspnoea. Often with repeated exacerbations which usually impact upon quality of life, reduced exercise capacity and fatigue.	30 to 50% of predicted FEV1/FVC < 0.7
4	VERY SEVERE	Appreciably impaired quality of life due to SOB. Possible exacerbations which may even be life threatening.	<30% of predicted or 50% with chronic respiratory failure FEV1/FVC < 0.7

However, although the above criteria are used by clinicians to establish the severity of COPD, the cut-off points have not been clinically validated. Use of these fixed ratios could therefore lead to over diagnosis of COPD in the elderly, due to changes in lung volumes as part of the process of aging (Rabe et al., 2007).

1.4 Symptoms of COPD

The present lived experience of people with COPD is largely determined by the symptoms they experience as they carry out their activities of daily living and this section of this chapter will examine these symptoms in more detail.

1.4.1 Breathlessness (dyspnoea)

Breathlessness is the symptom that most people with COPD describe as their most distressing and disabling (Williams, 1993). Dyspnoea is defined as an awareness of increased inspiratory effort which is unpleasant and recognized as inappropriate (Brewis, 1991). The sensation of dyspnoea is subjective, although clinicians may be able to observe signs such as rapid breathing or the use of accessory respiratory muscles (Cole & Mackay, 1990). Dyspnoea occurs when there is an increasing demand for ventilation, which cannot be matched by the patient's ability to respond to that demand (West, 2008). This increasing demand can be explained in terms of inefficient gas exchange, which takes place in the capillaries around the walls of the alveoli (Fig.1.1, p.22). Blood from the heart, which is low in oxygen and high in carbon dioxide, takes up oxygen and gives up carbon dioxide into the alveolar gas, by the process of diffusion (Cole & Mackay, 1990). Damage to the alveoli caused by emphysema results in inefficient pulmonary gas exchange, which leads to low levels of oxygen and high levels of carbon dioxide in the blood leaving the lungs. Low oxygen levels can be caused by low transfer factor, the transfer of oxygen across the respiratory membrane and a mismatch of ventilation perfusion. A high level of carbon dioxide is due to hypoventilation and poor ventilation at lung level. In addition, weak respiratory muscles due to hyperinflation of the lungs leads to this issue. Emphysema patients, in particular, hyperventilate and at first have only low oxygen and later as the disease progresses the carbon dioxide levels begin to increase. As a result, the imbalance between the respiratory demand and actual ventilation leads to the sensation of dyspnoea (Cole & Mackay, 1990).

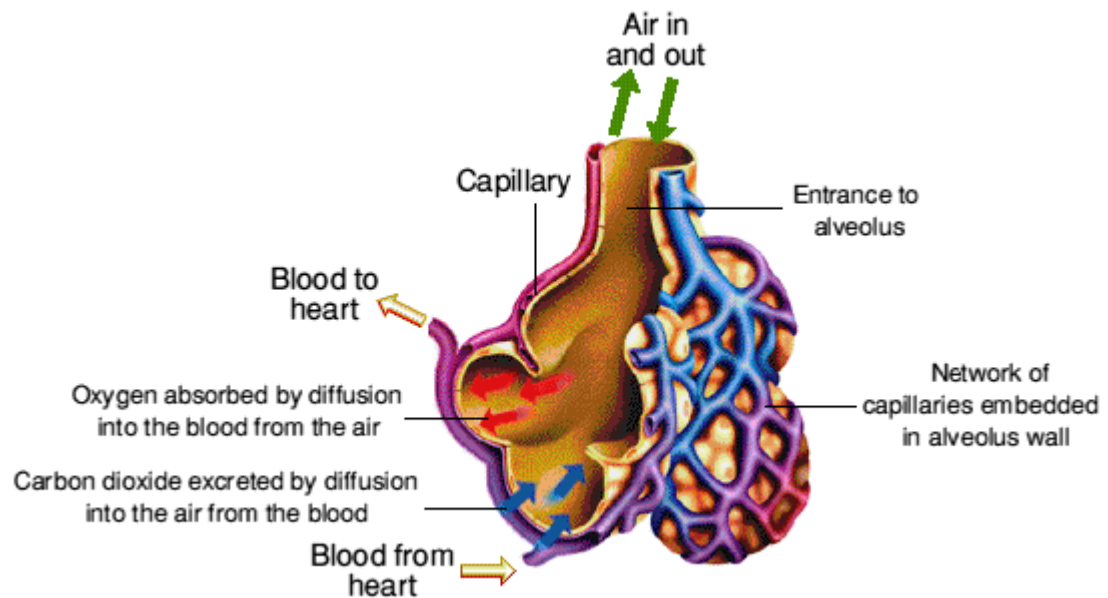


Fig 1.1 Gas exchange in the alveoli of the lungs (taken from <http://www.mcqueens.net/mcqueen-ntl/dis/toc/Pt20.html>)

Attacks of breathlessness can occur on exercise but in COPD patients, it can happen suddenly and unexpectedly, even at rest. Consequently, patients may feel they are fighting for their lives during these attacks and fear and panic are understandable responses (Williams, 1993). Sometimes there may be a loss of bladder control, with associated feelings of humiliation and shame (Williams, 1993).

Breathlessness can also lead to reduced calorific intake and in combination with the increase in metabolism brought about because of the workload of breathing, may lead to loss of weight and nutritional deficiencies. If the patient's Body Mass Index (BMI) falls below 21 kg/m², referral to a dietician and appropriate supplements will be recommended (Russell et al, 2012).

1.4.2 Cough and sputum production

The other main symptom of COPD is a chronic cough with an excess of sputum production. This is a clinical manifestation of chronic bronchitis and affects around 15% of males and 5% of females in the UK (Bourke & Burns, 2011). Cough has been found to be a significant predictor of decline in patients with established COPD (Smith

& Woodcock, 2006). Expectoration of the excess sputum is a problem causing considerable distress and embarrassment, particularly in social situations and can be physically debilitating (Williams, 1993). Obviously, this has a significant effect on the individual's quality of life. However, evidence from patient health status scores appear to show that, as the disease becomes more severe, breathlessness rather than cough becomes increasingly important (Smith & Woodcock, 2006).

1.4.3 Fatigue

An abnormally low level of oxygen in the blood is called hypoxaemia and a high level of carbon dioxide is referred to as hypercapnia. These can lead to hypoxia where the tissues in the body are deprived of oxygen. Low oxygen and high carbon dioxide may both cause fatigue. Individuals with COPD often talk of fatigue and lack of energy synonymously with breathlessness and speak of their tiredness as being a result of not being able to get enough oxygen (Williams, 1993).

1.4.4 Severity Measures for COPD

In addition to lung function tests, carried out by spirometry, there are several measures commonly used to establish the severity of COPD. These include:

- The **6-minute walk test (6MWT)** (Balke, 1963). This is designed to test exercise capacity. This is described as a simple and well-tolerated test which has been validated and standardized and reflects everyday activity.
- The **Medical Research Council (MRC) dyspnoea scale** (Fletcher, 1952). This is a self-applied 5-point instrument, which has been widely used but has scarce clinical data on validation, responsiveness and sensitivity.
- **St. George's Respiratory Questionnaire (SGRQ)** (Jones et al., 1992). This measure is widely used as an indicator of health status. It covers symptoms,

activity and psychosocial impact but is time-consuming to complete and analyse.

- **Chronic Respiratory Disease Questionnaire (CRQ)** (Guyatt et al., 1987). This also measures health status by asking the patient to recall the five most important activities that caused breathlessness over the last two weeks. It is commonly used in rehabilitation trials and is sensitive to treatment but its limitations include: it is not interchangeable with other disease-specific instruments and is not suitable for comparison between individuals.
- **BODE – multi-dimensional scoring system** (Celli et al., 2004). This scale has four components: Body mass index (BMI), Obstruction (FEV1), Dyspnoea (MRC scale) and Exercise capacity (6MWD). It is straightforward and has greater power than the individual scales but drawbacks include the fact that it does not assess the effects of therapies and the FEV1 categories are not consistent with the GOLD staging (see above).
- **COPD Assessment Test (CAT)** (Jones et al., 2009). This comprises of a short, simple questionnaire with good measurement properties (Jones et al., 2009)

1.4.5 Exacerbations

In COPD and in chronic bronchitis in particular, the mechanism that acts as a defence against infective agents is disrupted and viral infections are able to take hold in the bronchial tree (Bourke & Burns, 2011). Resulting infection provokes further inflammation causing increased cough and production of yellow sputum, then, and a vicious circle of infection and inflammation is set up (Bourke & Burns, 2011). These exacerbations of COPD become more frequent as the course of the disease develops and, in the advanced stages of the condition, pneumonia and pleurisy may develop (Cole & Mackay, 1990). Patients need to be vigilant with regards to changes in their condition e.g. sputum colour, which may indicate the presence of an infection and the need to obtain treatment.

1.4.6 Cor pulmonale

Chronic hypoxaemia, resulting from poor ventilatory function in COPD, causes the pulmonary blood vessels to constrict. When this happens in the lung it leads to pulmonary hypertension, which is defined as having a pressure in the pulmonary artery $>25\text{mm/Hg}$ at rest (Bourke & Burns, 2011). This pressure in the blood entering the right side of the heart from the lungs leads to enlargement (hypertrophy) of the right ventricle of the heart, known as cor pulmonale (Fig. 1.2). Symptoms in COPD patients which indicate the presence of cor pulmonale are increased pressure, causing enlargement, in the jugular vein of the neck and accumulation of fluid which causing the ankles to swell (peripheral oedema) (Bourke & Burns, 2011). Patients at this stage of the disease may be given diuretic treatment to reduce the swelling, and long-term oxygen therapy (LTOT).

Cor pulmonale, or right-sided heart failure, is an enlargement of the right ventricle due to high blood pressure in the arteries of the lungs usually caused by chronic lung disease

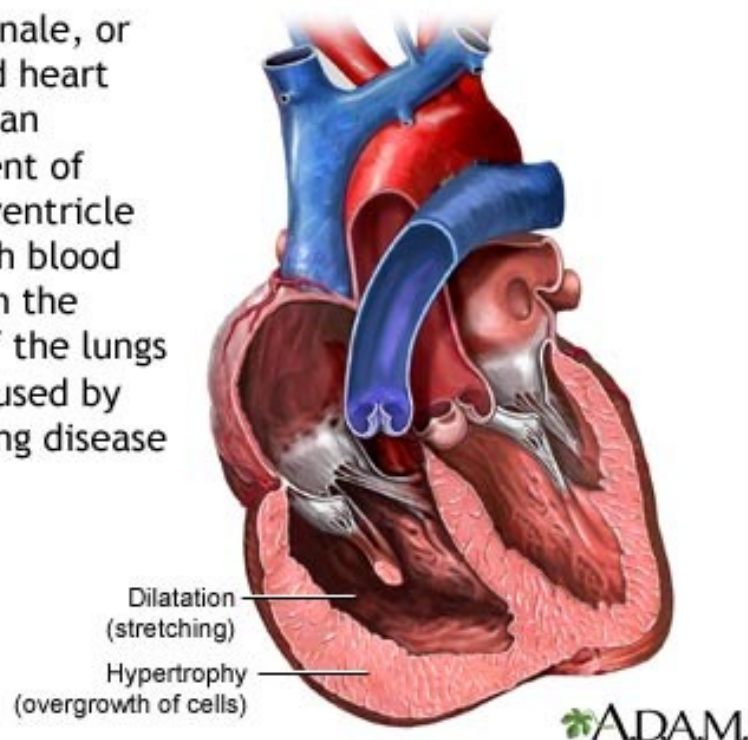


Fig 1.2. Cor pulmonale: taken from health.allrefer.com

1.5 Interventions for COPD

Although COPD is a chronic, progressive condition, there are several approaches used by healthcare professionals to alleviate symptoms and to slow down the progression of the disease. The following section of the chapter describes those interventions that will be most commonly encountered by participants in the study.

1.5.1 Smoking cessation

Treatment with the aim of achieving long-term or permanent abstinence from tobacco smoking is recommended to be carried out as a specific, primary intervention (Celli et al., 2004). All tobacco users should be offered appropriate treatment and support. Recommended treatments are, nicotine replacement therapy (NRT), varenicline or bupropion as appropriate and these should be accompanied by social and behavioural support (NICE, 2010).

Silagy et al. (2007) reviewed the evidence for effectiveness of various types of NRT. They concluded that all available products at that time; gum, transdermal patch, nasal spray, inhaler and sublingual tablets or lozenges, increased the odds of quitting smoking by between 1.5 and 2 fold (Silagy et al., 2007). However, the same review found that there was no evidence that one type of NRT worked any more effectively than the others (Silagy et al., 2007).

More recently, electronic cigarettes (e cigarettes) have been used as an aid to smoking cessation. These are battery powered and deliver nicotine without combustion or smoke. An online survey of people who started using a new brand of e cigarette found that the rate of smoking abstinence at the six-month point was 31%, with 34.3% of this group using no nicotine containing products at that time (Siegel et al., 2011). However, although 5000 people were invited to take part in the study, the response rate was 4.5% and a more rigorous study would be required before any conclusive evidence for the effectiveness of e cigarettes can be established.

1.5.2 Pharmaceutical treatments

Although smoking cessation cannot reverse the decline in lung function of those with COPD, it remains the only intervention that has been proven to modify the disease and preserve lung function (Bourke & Burns, 2011). However, whether patients continue smoking or not, there will still be a requirement for pharmaceutical intervention in the treatment of COPD. The National Institute for Clinical Excellence (NICE) in their 2010 update on the treatment of COPD, recommend inhaled therapies as a first-line treatment for COPD. Short acting Beta₂ agonists (SABA) or short acting Muscarinic antagonists (SAMA) are the first line of treatment with long acting Beta₂ agonists (LABA) or long acting Muscarinic antagonists (LAMA) for maintenance therapy. Inhaled corticosteroid (ICS) treatment is advised if symptoms are more severe and this has been found to be most effective in the form of a LABA/ICS combination inhaler (NICE, 2010). A combination inhaler, such as Seretide or Symbicort, which contains a corticosteroid along with a long-acting bronchodilator, has been found to have a beneficial effect on the frequency of exacerbations, reducing this frequency by around 30% (Bourke & Burns, 2011).

NICE (2010) also advises that the most appropriate delivery system must be used for the individual patient. Where metered dose inhalers are used, technique must be checked by a healthcare professional at regular reviews. Delivery of the medication to the lungs falls if the technique is incorrect and, in some cases, delivery may approach zero (Bourke & Burns, 2011). Spacer devices, which distance the inhaler from the mouth and deliver a fine aerosol of small particles, are recommended where inhaler technique is poor. They can improve delivery to the lower lungs whilst avoiding the need for coordination of inspiration and actuation of the inhaler (Bourke & Burns, 2011). Breath-actuated inhalers, where the inhaler is actuated as the patient breathes in, also reduce the need for coordination but do require a good inspiratory flow rate to operate them (Bourke & Burns, 2011). Nebulisers are advised only for the purpose delivering medication in situations of distressing or disabling breathlessness (NICE, 2010).

Table 1.2. Inhaled treatments for COPD

Short-acting bronchodilators (can be used at all stages of COPD)	
Short-acting beta-2 agonists (SABA)	Salbutamol 200mcg as needed Terbutaline 500mcg as needed
Short-acting muscarinic antagonist (SAMA) needed (aerosol inhaler)	Ipratropium 20-40mcg as needed (dry powder inhaler)
Ipratropium 40-80mcg as needed (dry powder inhaler)	
Long-acting bronchodilators (can be used at all stages of COPD)	
Long-acting beta-2 agonists (LABA)	Formoterol 12-24mcg twice per day
	Salmeterol 50mcg twice per day
	Indacaterol 150mcg once per day
Long-acting muscarinic antagonist (LAMA) via Respimat	Tiotropium 5mcg once per day Tiotropium 18mcg once per day via Handihaler
Handihaler	
Long-acting bronchodilator and inhaled corticosteroid combination (used in more severe disease and with repeated exacerbations)	
Symbicort (licenced for use if FEV1<50% pred) formoterol 12mg (one puff twice per day)	Budesonide 400mcg and Turbohaler 200/6
Seretide (licenced for use if FEV1<60% pred) 500mcg	Salmeterol 50mcg and fluticasone 500mcg
	Accuhaler 500 (one puff twice per day)

Table adapted from Bostock-Cox (2010)

The maintenance use of oral corticosteroid therapy for COPD is not recommended but, if this therapy is used long-term, the patient must be monitored for the side effect of osteoporosis and, if appropriate, given prophylaxis (NICE, 2010).

A further oral medication which can be prescribed after a trial of short and long-acting bronchodilators is Theophylline in a slow-release formulation (NICE 2010). However, it is important to measure the blood theophylline at periods during treatment to ensure that the optimum dosage is being administered, as side effects such as nausea and tremor may occur, with the risks of over dosage including abnormal heart rhythms and epileptic seizures (Brewis, 1991).

The NICE (2010) guidelines recommend long-term oxygen therapy for the following patients: those with an FEV<30% predicted; cyanosis, polycythaemia; peripheral

oedema; raised jugular vein pressure; or oxygen saturation <92%. It is prescribed where the level of oxygen in the blood is dangerously low and there is potential for damage to the vital organs. The oxygen needs to be administered for at least 15 hours a day to be effective (NICE, 2010). Ambulatory oxygen therapy is available in the form of portable oxygen cylinders in order that people may leave their homes while they are receiving oxygen therapy. In recent years, the invention of oxygen concentrators, which use room air, has been advantageous as they are less cumbersome and do not have the same risk of combustion as cylinders of compressed oxygen.

1.5.3 Pulmonary Rehabilitation (PR)

Although bronchodilators often produce only a small improvement in lung function, they are often helpful in terms of enabling the patient to carry out everyday activities (Sterling, 1983). However, treatment of COPD requires a more holistic approach to achieve the maximum benefit in terms of improvement in quality of life and in enabling individuals to continue with their activities of daily living (ADLs) for as long as possible. As a further intervention, therefore, pulmonary rehabilitation (PR) should be offered to all appropriate people with COPD, including those who have had a recent exacerbation (NICE, 2010). A programme of PR should be regarded by the person who refers the patient as a fundamental treatment for COPD rather than an optional extra (Bolton et al., 2013). Furthermore, patients with COPD should be referred for pulmonary rehabilitation regardless of their smoking status (Bolton et al., 2013). This is an important consideration as, in a qualitative study carried out by Halding and Heggdal (2010) it was found that smokers experienced stigma and self-blame which added to the strain of their illness. This was supported by an interview study with COPD patients in the Republic of Ireland, where patients reported that they did not attend GP or nurse appointments because they felt that they would not be treated for their COPD unless they gave up smoking (Hyde et al., 2013). In the same study, GPs reported that the reluctance of smokers to visit the GP practice, and the associated anxiety about their previous experiences in primary care, meant that

they would wait until their illness became acute before they would seek help (Hyde et al., 2013).

PR is an intervention usually delivered to groups over a period of 12 to 16 sessions and the NICE guidelines (2010) recommend that it should include the following items: physical training; disease education; nutritional, psychological and behavioural intervention. PR also includes smoking cessation advice and support and in many cases may offer advice on such varied topics as travel, finance and marital relationships. Further NICE guideline (2010) recommendations include the following: that PR should be offered to patients who feel functionally disabled by their COPD; that PR should be held at physically accessible places and at a suitable time for patients; and that PR should include multidisciplinary interventions, tailored to the individual patient's needs.

In a systematic review of the literature, Lacasse et al. (2009) found that Pulmonary Rehabilitation produces significant improvements in several domains of quality of life, including breathlessness, fatigue, emotional function and mastery in COPD patients. In addition, evidence in recent literature has shown support for the use of pulmonary rehabilitation in the effective management of psychological morbidity in COPD but it is uncertain which components of PR lead to this improvement (Coventry, 2009).

1.5.4 Lung surgery

Lung surgery may also be available to COPD patients in a small number of very specific circumstances. The three main types of surgery, which may be suitable for some COPD patients, are bullectomy, lung volume reduction and lung transplantation. Bullectomy is the removal of large cystic areas (bullae) which form in some patients with emphysema (West, 2008). Lung volume reduction is surgery performed to remove functionally useless areas of lung, which have been damaged by emphysema. This type of surgery aims to restore some of the elastic recoil in the lungs, which has been lost due to the destruction of the alveoli (Bourke & Burns,

2011). The lack of organ donors severely limits the use of lung transplantation for those with advanced disease (Bourke & Burns, 2011).

Overall, it is recommended that care of COPD should be delivered by a multi-disciplinary team (NICE, 2010). *“An effective approach to COPD requires cooperation of all healthcare providers working across primary and secondary care boundaries. Many agencies will and should be involved, including GPs, palliative care services, district nurses, hospital specialist services and social services. Patients can be educated about their disease and empowered to self-manage, so that they can use health service providers in a more effective manner”* (Russell et al., 2012, p262).

1.6 Psychological comorbidities

People who have COPD frequently experience comorbidities i.e. *“the co-existence of two or more chronic conditions, where one is not necessarily more central than the others”* (Boyd & Fortin, 2010, p.453). Population based evidence has shown that the prevalence of cardiovascular disease and the incidence of hospital admission for major cardiovascular events is higher in people with COPD than in the general population (Curkendall et al., 2006). Another study that looked at cardiovascular disease along with other comorbidities in COPD patients, found that rates of angina and myocardial infarction were higher in this group than in people without COPD. The same research also found that rates of bone problems such as fractures and osteoporosis, and smoking related problems such as pneumonia, were higher in COPD patients (Soriano et al., 2005). However, psychological comorbidities have also been found to be higher among people with COPD.

1.6.1 Anxiety and COPD

The incidence of co-morbid anxiety in COPD patients is far higher than in the general public and this has an impact on their quality of life. Studies, which used the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) to measure levels of

anxiety, found varying levels of anxiety in COPD patients. Levels of anxiety in these studies ranged from 10% (Xu et al., 2008) to 49% (Funk et al., 2009). A study by Vogeles and Leupoldt (2007) used clinical interviews to assess the mental health of COPD patients and found that 55% of the COPD group had a diagnosis of mental disorder, compared with 30% in the control group. Furthermore, they found that the most common sub type of mental disorder in the COPD group was a form of anxiety described as Panic Disorder with Agoraphobia (Vogele & von Leupoldt, 2008). A recent systematic review by Willgoss and Yohannes (2013) found that the prevalence of anxiety in COPD patients ranged from 10-55% in in-patients and 13-46% among outpatients. Healthcare professionals are advised to look out for the presence of anxiety and depression in COPD patients who are hypoxic, have severe dyspnoea or have had hospital treatment for an exacerbation (NICE, 2010).

Patients with COPD therefore will need both psychological and social support (Russell et al., 2012). It is important to recognize psychosocial risk factors affecting the management of the condition and patient-led initiatives, such as the Breathe Easy groups (national patient groups supported by the British Lung Foundation) can provide valuable support for people with COPD (Russell et al., 2012).

Diagnosis of anxiety can be made according to the criteria laid down in the Diagnostic and Statistical Manual of Mental Disorders (DSM), which is published by the American Psychiatric Association. DSM was first published in 1952 and lists the different categories of mental disorder with the criteria for diagnoses as published by the American Psychiatric association. Psychiatrists previously diagnosed patients using the theory that anxiety resulted from unconscious conflict in the mind. The present definitions are based on external and reported symptoms rather than theories regarding their cause. The latest DSM-5 update was in 2013.

The section concerning anxiety disorders in the DSM-5 includes the diagnostic criteria for panic disorder, specific phobia, agoraphobia and social anxiety disorder. Changes made to the previous version of the DSM with respect to anxiety disorders include the removal of obsessive compulsive disorder (OCD) into a separate classification and the addition of separation anxiety disorder.

According to the mental health support website, MIND (2015), there can be numerous physical symptoms of anxiety. They include nausea, tense muscles and headaches, sweating or hot flushes, irregular heartbeat, difficulty sleeping, panic attacks and, arguably of most relevance to people with COPD, faster breathing. Psychological symptoms of anxiety include feeling tense, nervous and on edge, having a sense of dread or fearing the worst, dwelling on negative experiences and an inability to concentrate.

1.6.2 Prescribed treatments for anxiety

Information from the MIND website (2015) says that there are several courses of treatment available through the GP. Firstly, there are the talking treatments of counselling and psychotherapy. These treatments are designed to help with how a person is feeling; some will also look into the reasons why an individual may be experiencing anxiety. These usually consist of six to twelve sessions.

Secondly, a patient with anxiety may be referred for a course of cognitive behavioural therapy (CBT). This treatment is recommended by the National Institute for Health and Clinical Excellence (NICE) (2010) for anxiety and panic disorders. CBT is short-term therapy, which encourages people to develop new ways of thinking and work out strategies for managing anxiety. This can be carried out in face-to-face consultations, as group therapy or on line.

NICE also recommend exercise on prescription to help to alleviate symptoms of anxiety. In this form of treatment, patients are referred to a qualified trainer for specialised exercise advice and motivation. Unfortunately, this is not available in all areas of the UK although individually tailored exercise regimes are a part of most PR programmes.

1.6.3 Self-help for anxiety

The MIND website (2015) gives some recommendations for self-help to people suffering from anxiety symptoms. For example, breathing exercises or relaxation techniques are suggested to control symptoms. These can be learnt in classes or on-line. Secondly, assertiveness training, again available as group sessions or on-line, can teach people how to handle difficult situations and may increase confidence and promote relaxation. Complementary therapies such as meditation, aromatherapy, massage, reflexology and hypnotherapy are also listed as possible ways of alleviating symptoms of anxiety and reducing breathing difficulties.

A further intervention, that is recommended by NICE for recurrent depression but can also help some people with anxiety, is Mindfulness-based cognitive therapy (MBCT) (Zindel et al., 2002). This is based on mindfulness-based stress reduction (MBSR) techniques that were developed for people with chronic pain, hypertension or heart disease in addition to depression and anxiety. This is usually taught in groups and teaches people how to be more aware and mindful about what they are experiencing. It can be done in conjunction with yoga and relaxation training.

MIND also advises that leading a healthy lifestyle can contribute to a reduction in stress and anxiety. It recommends walking or running, at an individual's own pace, alone or in a group and advocates eating healthily and avoiding alcohol to help with sleeping problems. In the context of the physical and psychological symptoms that can be experienced by those with COPD, the penultimate section of this chapter will discuss ideas that have been proposed regarding possible changes within the healthcare system that may potentially improve the care of those with this condition.

1.7 The care of people with COPD – is there a need for change in the Healthcare System?

“It is now widely recognised that the care and support needed to live with a long-term condition requires a radical re-design of services, allowing patients to drive the care planning process” (Coulter et al, 2013, p2).

COPD kills around 25,000 people a year in England and Wales (National Statistics, 2008) and the condition accounted for 4.8% of all deaths in England between 2007 and 2009 (National End of Life Care Intelligence Network, 2011). According to the Department of Health (2011), COPD is the second most common cause of emergency admission to hospital and is one of the most expensive conditions in terms of the cost of acute hospital care in England (Department of Health, 2011).

It is acknowledged that the population of the UK is changing in that we now have an increasing number of older people. As many of these individuals will have one or more long-term conditions, resulting in a loss of ability to carry out some of their activities of daily living, they will require an increased amount of input from health and social care systems. The high incidence of comorbidity in people with COPD often leads to a reduction in their health-related quality of life. Commonly found comorbid conditions such as ischaemic heart disease, heart failure, normocytic anaemia, depression and anxiety also lead to an increase in hospitalization, mortality and healthcare costs (Barnes & Celli, 2009). Therefore, good management of COPD patients, optimising physical and mental functioning, and including secondary prevention not only focuses on improving patient experience but also reduces costs to health services.

However, despite the burden of COPD, both in terms of individual quality of life and financial burden to the NHS, the care of people with this long-term condition appears to fall short of that in some other developed nations and premature mortality from COPD in the UK was almost twice as high as the European (EU-15) average in 2008 (DOH, 2011).

The Department of Health suggests there is therefore a need for changes in the care of those with COPD in the UK. In outlining this requirement for change, the Department of Health Outcomes Strategy for COPD and Asthma in England (2011) states that if more people with COPD can be kept well and in their own homes, more resources will be released to benefit other people (Department of Health, 2011). However, the release of financial resources is only one of a number of measurable outcomes and not one that will have a direct impact on the quality of life of individual COPD patients. There is a growing shift in recent literature, towards more emphasis on patient-centred outcomes in the treatment of COPD. Although patient outcomes have largely been measured in terms of symptom relief and the measurement of FEV1, the effect of treatment on patient-centred outcomes such as dyspnoea and quality of life is now being widely considered (van der Molen & Cazzola, 2012). The move towards broader patient-centred issues and patient-determined outcomes of management is likely to lead to changes in service approaches, with a greater emphasis on quality of life.

1.7.1 Person-centred care

The term 'person-centredness' began in the 1940's when American psychologist, Carl Rogers used it to describe his approach to therapy. This differed in several ways from Freud's method of psychotherapy, which was prevalent at that time. Roger's person-centred approach was based around the concept that individuals should not be treated as objects, that they have a better knowledge of their own condition (than the therapist does) and they are able to set their own goals (Leplege et al., 2007).

Slater (2006) carried out a literature review in order to develop a concept analysis of the term person-centredness and discussed how, in the relevant literature, it is often confused with, or used interchangeably with, patient-centredness. Slater suggests that, in both phrases, centredness indicates that the person or patient is the axis of the consideration but that a person is seen as an individual, whereas a patient is regarded as someone in need of care (Slater, 2006). She adds that, in person-centred

care, the hub of the care is the person and not the disease and therefore this can be applied across all areas of healthcare (Slater, 2006). This is particularly relevant to a chronic illness such as COPD where the individuals involved require input from healthcare workers from different disciplines. The terms “person-centred care” and “patient-centred care” are often used interchangeably in the literature.

A major challenge facing the implementation of patient-centred care in the healthcare system is that the meaning of the term is interpreted differently by the members of the wide range of professional and stakeholder bodies involved in the healthcare system. These different meanings are a reflection of the particular roles and backgrounds of health professionals, educationalists, managers and patient representatives (Gillespie et al, 2004). In their interview study, Gillespie et al (2004) found that the people they spoke to who were members of health professionals groups tended to adopt a medical model of patient-centred care, which stressed the need to inform patients and engender their trust. In contrast, respondents who came from user groups described patient-centred care in terms of the whole person model of health and talked of the need for patients to be involved in the planning and delivery of services (Gillespie et al, 2004). This study highlighted the requirement for policy makers, managers and other health professionals to recognize that patient-centred care covers a spectrum of potential activities from public involvement in planning to individual interactions between patients and clinicians (Gillespie et al, 2004).

However, Kitson et al (2012) in their review of the literature did identify three core themes of patient-centred care: patient participation and involvement, the relationship between the patient and the healthcare professional and the context where the care is delivered. Although they concluded that these elements indicated that there was a common conceptual source, they too found that different professional healthcare groups, from policy-makers and management through to the level of individual patient/clinician encounters, tended to focus on different elements of these themes, according to their roles and professional interests (Kitson et al, 2012).

Glass et al, 2012 proposed a model of person-centred healthcare for older people with chronic illness in Australia, designed to improve patient self-care and thus reduce the number of repeat hospital admissions. The context from which the model emerges, stresses the importance of good interpersonal communication between healthcare professionals and their patients and of the enhancement of 'valuing self' in order to achieve good outcomes in self-care (Glass et al., 2012). The philosophical framework that guides the proposed intervention (Fig. 1.3) stresses the need for healthcare professionals to work collaboratively with patients, listening to their narratives concerning their health status, sharing ideas and visions and creating a place of emotional safety, which contributes to self-growth and improved lifestyles (Glass et al., 2012).

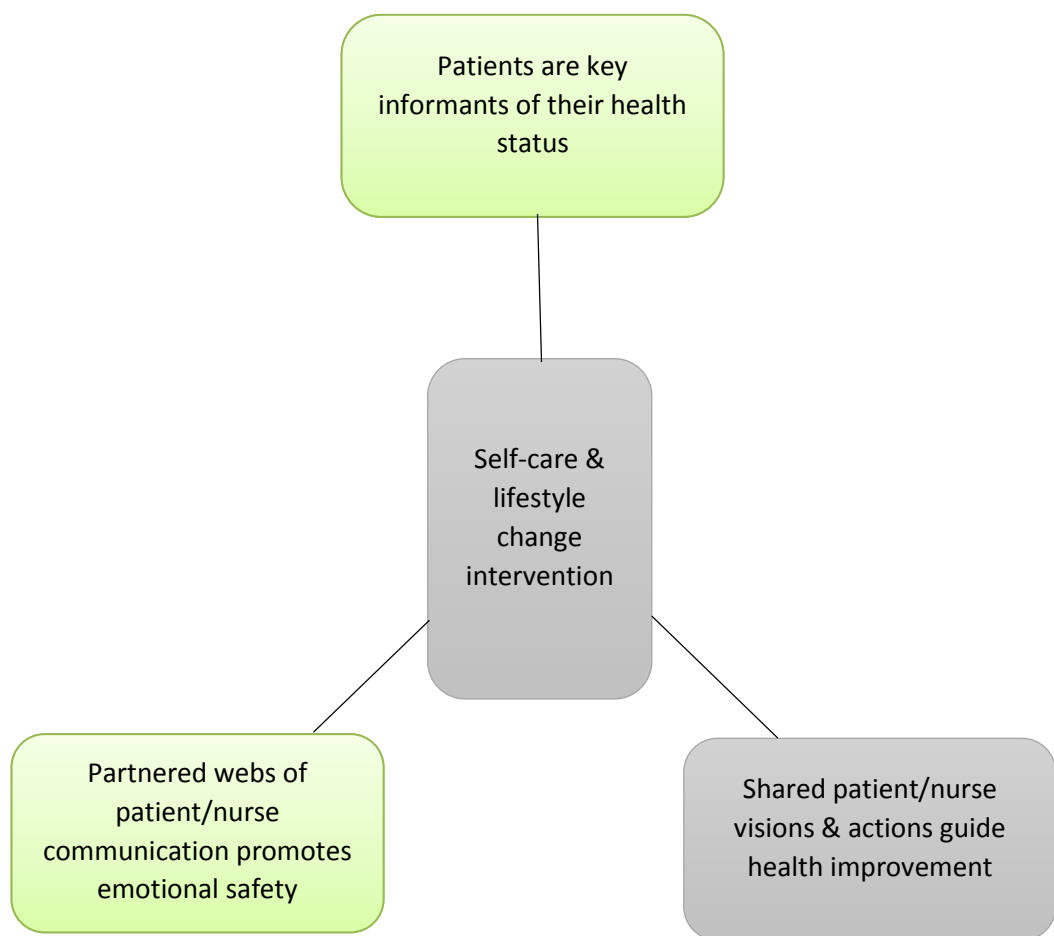


Fig 1.3. Philosophical framework – self-care and lifestyle change intervention.
(Adapted from Glass et al., 2012)

Elbourne and LeMay (2012) looked at the impact and effectiveness of a person-centred intermediate care (PCIC) facility for older people housed in a total care living complex run by a charity in the UK, during its first two years of functioning. The aim of the facility was to provide intermediate care for people who require rehabilitation after early discharge from hospital or as an alternative to hospital admission. In addition to the person-centred philosophy of the centre, it had an innovative approach to care involving a multidisciplinary team derived from the charity, the local hospital and primary care trust. Although there had been some practical difficulties in implementing PCIC, the outcome for the service users was positive with the majority returning to their own home, showing a statistically significant increase in functional improvement, feeling pleased with their recovery and indicating that they felt they were treated with kindness, dignity and respect (Elbourne and LeMay, 2012). However, it was apparent that there were some problems with miscommunication when implementing person-centred care. It was found that it was necessary to emphasize to patients and families that that person-centred care would involve a partnership between service users and providers, in which patients would be required to take part in carrying out activities of daily living rather than having things done for them (Elbourne and LeMay, 2012).

In order for healthcare professionals to be able to implement person-centred care in practice, appropriate training is required. Steenbergen et al. (2013) sought the views of nursing students attending two different universities, one in Scotland and one in the Netherlands, about their training with respect to person-centred care. The study found that, although students from both universities felt that person-centred care should be an important part of the curriculum, there were considerable differences in the reported focus and delivery of this between the two universities (Steenbergen et al., 2013). It would be relevant to look in more detail at how person-centred care is taught and assessed in a number of UK universities.

Individualized care is an alternative term used for care that is tailored to patients' individual requirements. Suhonen et al (2000, 2005) developed the Individualized Care Scale (ICS), to measure this concept. They defined individualized care as *"a type of nursing care delivery in which nurses take into account patients' personal*

characteristics, their clinical condition, their personal life situation and their preferences with regard to promoting patient participation in decision making” (Suhonen et al., 2010 p.1036). In a study into nurses’ perceptions of individualized care, using the ICS, it was found that all the nurses felt that they supported the individuality of patients well. However, the findings varied according to the organization in which they worked, with mental health nurses having the most positive perceptions and those working in long-term inpatient care the lowest (Suhonen et al, 2010). In a similar study to assess patient satisfaction using the ICS, it was found that individualized care resulted in higher patient satisfaction but that the correlation with health related quality of life was low, although still statistically significant (Suhonen et al., 2005). Both studies were carried out in Finland and, although of interest to the present study, may not be indicative of perceptions in the UK healthcare system.

Coulter et al (2013) in their report for the Kings Fund present the House of Care model to illustrate a whole-system approach to healthcare for people with long-term conditions. In this model, the base of the house is the local commissioning plan, the walls represent the informed patient and the healthcare professional (who is committed to working in partnership), the roof represents the organisational systems and processes and care planning is at the centre of the house. For this approach to be successful, all parts of the house need to be in place and be interdependent.

The final part of this chapter will explore the importance of exploring the lived experience of people with COPD in order to understand whether their psychosocial needs are being met by the existing healthcare system.

1.8 The lived experience of people with COPD

“It is as important to know the patient who has the disease, as it is to know the disease which the patient has” (McCormick, 1996, p.668).

In a review of the literature around patient-centred care, Bensing (2000) found that patients differed in their views of what is required in a patient-centred consultation. For example, some patients preferred to limit their discussion with the doctor to the biomedical factors concerned with their condition and were uncomfortable when a clinician explored psychosocial factors (Bensing, 2000). In addition, it was shown that patients expressed differences in the amount and type of information they wanted to receive about their illness and dealt with medical information in different ways (Bensing, 2000). This illustrates the need to understand the lived experience of the individual and their expectations in order for healthcare professionals to deliver the most appropriate care for that person.

In their interview study with COPD patients who attended a PR programme in Norway, Halding and Heggdal (2012) found that being part of a group strengthened the participants’ awareness of their remaining health and made the situation seem less dramatic. However, in their conclusion, they recommended that healthcare professionals should assess each participant’s lived experience and needs, before, during and after the duration of the PR course (Halding & Heggdal, 2012).

As early as 1998, Skilbeck et al. identified that COPD patients receiving palliative care had unmet needs. They found that respiratory nurse specialists, employing a holistic approach to care in attending to the patients’ social and psychological needs in addition to their physical care were best placed to meet these unmet needs (Skilbeck et al., 1998). Elkington et al (2004) later published similar findings in their interview study with carers of COPD patients who had recently passed away. They found that some patients had only prescription contact with their GP practice in their final year of life and only three carers mentioned home visits from a respiratory nurse, reporting that this contact was valued (Elkington et al., 2004).

Patients also need to have adequate knowledge of the services available to them in order for them to make informed decisions about their own healthcare. As part of the National COPD Resources and Outcomes Project (NCROP), Roberts et al (2009) conducted focus groups with COPD patients to assess their views about three key services offered by the NHS: non-invasive ventilation (NIV), early discharge schemes and rehabilitation. Their findings indicated that, although the patients had made important suggestions about patient-focused care in the context of service development, they suffered from a lack of education and knowledge about some of the key recent NHS medical service developments (Roberts et al, 2009). Although most of the COPD patients in the focus groups had experience of pulmonary rehabilitation, only 30% had direct experience of an early discharge scheme, with 50% of the remainder of the sample having no understanding of this service, and the majority of them had no understanding of the concept of NIV (Roberts et al, 2009).

The development of services for COPD patients' needs input acquired from actively listening to patients' individual accounts (Barnett, 2005). Kaptein et al. (2009) also talk about the importance of gaining insight into the COPD patients' perceptions of their situation and incorporating these into the philosophy of care.

In addition, as the prevalence of COPD is expected to rise in the coming years and more patients are to be cared for in the home, there will be a growing need to be aware of the needs of carers of people with this condition. These individuals are predominantly caring for family members at home and they will need adequate, and appropriate, information and support in order to carry out their role of providing care whilst maintaining their own physical and emotional health (Caress et al., 2009).

In conclusion, therefore, having spent almost twenty years working on the front line of the primary care service and having combined this with my academic work, I progressed to working in research, exploring the care of older people with long-term conditions, an area of healthcare that is of particular interest to me. The care of older people with long-term conditions is becoming increasingly important to the healthcare system in the UK and in 2013, the then Conservative and Liberal Democrat

coalition produced a mandate setting out their plans for the healthcare system during their term in government. In this document, they predicted that, by 2018, nearly three million, predominantly older people, would be living with three or more long-term conditions. They continued by stating that, in order to meet these changing needs, the different parts of the NHS need to work together more effectively and that there needs to be joined-up care involving other organizations, such as social services (DOH, 2013). NHS England (2015) have set out their action plans for dealing with these challenges and these proposals include: helping patients to take charge of their care, enabling good primary care, ensuring continuity of care and ensuring parity of esteem for mental health.

According to NHS England (2015), 'Ensuring that people's views are heard at all levels and across all parts of the healthcare system is essential for creating and delivering better health and care services'. In order to achieve the best outcomes for patients and the healthcare system alike, it is therefore important to be aware of the experiences and perceptions of both patients and the healthcare professionals who care for them. This study aims to explore the lived experience of people with COPD and to explore the views of healthcare professionals involved in the care and treatment of patients with COPD in order to answer the research question "The lived experience of people with COPD: How are health providers meeting their psychosocial needs?" My objectives in carrying out this research study are "To establish the extent to which the physical and emotional symptoms experienced by individuals with COPD affect their quality of life and ability to carry out their day-to-day activities" and "To understand how the experiences of clinicians in treating people with COPD are related to the perceived needs expressed by the patients".

CHAPTER 2 - LITERATURE REVIEW

2.1 Introduction to the literature review

Chapter 1 outlined the basic considerations in COPD, this chapter now reviews examples of current literature, mainly those published from 2010 onwards, which are relevant to the research question and aims of the study. A search of the literature was carried out in order to establish a theoretical framework for the study and to identify other studies in the field, which would inform and support my research. In accordance with these aims, my search strategy began using the database CINAHL and using search terms related to the topic, including; COPD, lived experience, long-term conditions, treatment and healthcare. As the care of people with long-term conditions, such as COPD, is subject to recent changes in policy and practice, it was decided that literature from 2010 onwards would provide the most relevant and up-to-date information for this study. Furthermore, the search was updated, using CINAHL and Google Scholar, throughout the period of study, in order to maintain awareness of the most recently published literature in the field.

Whilst the choice of literature began by searching databases, this was developed by following up references and citations in order to seek out further literature of particular relevance to the topic of peoples' experience of living with COPD and of the healthcare they receive. Publications were reviewed in terms of their relevance to major factors that influence the lives of people with COPD and the healthcare professionals who work with them. My interest was drawn to studies in which the experiences of COPD patients had been explored, either quantitatively or qualitatively, or where the perceptions of healthcare professionals were sought. In particular, literature concerned with the psychosocial needs of COPD patients was included.

Literature published prior to 2010 was excluded with the exception of seminal texts, which provided necessary background knowledge, or research findings slightly earlier than this date but still considered to be of relevance to the study. For example, a study conducted by Bailey et al. (2009) which explored the narratives of people

with COPD and found a variation in their explanations for the perceived cause of their illness, provided an insight which could be used to inform the choice of questions in the topic guide for the semi-structured interviews to be conducted in the present study.

As noted in chapter 1, an exploration of the lived experience of those with COPD needs to be grounded in an awareness of its causation and how its symptoms affect people's day-to-day lives. Therefore, the actual, and perceived, causes of COPD are the first topics for discussion in this review. In association with the causes of COPD, multimorbidity is something that affects many people with long-term conditions and psychological comorbidities, in particular are common in people with COPD. This can be a particular problem when anxiety and panic are present with breathlessness and studies that have examined the interaction of these conditions are particularly relevant.

In order to examine whether the healthcare system is meeting the needs of COPD patients, it is necessary to look at the recent literature around these needs and how these are perceived by patients and professionals as being met at present through interventions such as pulmonary rehabilitation. An important aspect of health care, particularly for those with long-term conditions, is the education and support required to enable patients to self-manage their condition. The concept of person-centred care and its application in patient-centred healthcare encounters are also examined in the literature in order to establish how these relate to the healthcare experiences of individuals with COPD and how healthcare professionals perceive the care they provide in this context.

2.1.1 Literature concerning the accepted and perceived causes of COPD

The review begins with a brief outline of the causes of COPD and how individuals' perceptions of the cause of their illness influence their lived experience. According to data from the National Collaborating Care Centre for Chronic Conditions (NCCCC, 2004), COPD is predominantly caused by cigarette smoking. However, it has been shown that some individuals regard respiratory ill health as an inevitable

consequence of their lifestyle and environment and, in addition, that some, ex or current, smokers experience self-blame and stigmatisation (Halding et al., 2011).

Small et al. (2012) examined the experiences of COPD patients and their carers in a former mining town in Yorkshire and found that there was a prevailing attitude in the community regarding the inevitability of respiratory ill health owing to the local industrial history. This had led to the local belief that their COPD was caused by experience in the coal-mining industry and the accompanying reluctance to accept that smoking may be a contributory cause (Small et al., 2012). Small et al. (2012) concluded that there is a need for local circumstances to be taken into account when dealing with the needs of patients with chronic illnesses.

Smoking cessation has been shown to be effective in reducing the risk of developing COPD and in slowing down its progression (GOLD, 2013). In the light of this evidence, two recent studies are considered that have looked at the experiences of people who continue to smoke despite having been diagnosed with COPD. Although both studies were qualitative studies with small sample sizes, the findings were of particular interest in terms of how healthcare professionals might best approach the topic of smoking cessation with this particular patient group.

Jonsdottir and Jonsdottir (2011) carried out a study with seven women who had been diagnosed with COPD more than ten years previously and who had repeatedly relapsed to smoking. They concluded that these women found the addiction to nicotine was overwhelming. Furthermore, they struggled with complex lives surrounded by ill health and other social problems, which led to them to continue to use smoking to relieve their stress (Jonsdottir & Jonsdottir, 2011). Wilson et al. (2010) carried out a qualitative study in which they interviewed six COPD patients who continued to smoke and found a number of themes emerging from their data. These included the experiences of participants who weighed up the costs and benefits of smoking only to conclude that smoking was the only enjoyment they had left in life. Others felt they could not achieve the goal of giving up smoking and resigned themselves to premature death, while others entered a cycle of guilt, diminished self-worth and low self-esteem, which, again, made it difficult even for them to attempt cessation (Wilson et al., 2010).

One of the psychosocial needs of patients with COPD may be a need for assistance with smoking cessation. However, in a society with a strong emphasis on tobacco control, those who have COPD, and are former, or current, smokers, may experience feelings of stigmatisation and self-blame (Halding et al., 2011). In a qualitative interview study carried out in Norway, it was found that the strong emphasis that healthcare professionals put on the patients' smoking habits was sometimes perceived as a lack of empathy rather than an expression of support (Halding et al., 2011). As a result, patients spoke about healthcare encounters in which they felt unsupported and how these consultations had generated feelings of guilt and self-blame (Halding et al., 2011). Some of the study participants also felt strongly that they were being exploited for the purposes of national advertising campaigns that used image of people in the oxygen-dependent stages of COPD to promote public smoking cessation.

Furthermore, Halding et al. (2011) found that some smokers in their study were reluctant to contact their doctors or nurses for treatment or advice because they felt that healthcare professionals discriminated against smokers and they would therefore be discredited as a patient. Although the sample for this study was small and the results are not generalizable, it is an important piece of research in the context of the present study. Halding et al. (2011) explored the lived experience of people with COPD through interviews and described how their feelings of self-blame and stigmatisation around smoking could become a barrier to receiving help with their psychosocial needs. In order to obtain a better understanding of how these barriers can be overcome therefore there is also a need to also hear how healthcare professionals experience the care they provide for COPD patients and what they perceive to be the barriers to the provision of this care.

Jonsdottir and Jonsdottir (2011) also found that participants in their study faced a lack of understanding or empathy from some healthcare professionals and Wilson et al. (2010) found that patients failed to access external support from the healthcare system, as they did not perceive them as being beneficial. Feelings of guilt and avoidance of seeking encounters with clinicians, for fear of being stigmatized were also apparent in these studies. Both Jonsdottir and Jonsdottir (2011) and Wilson et

al. (2010) concluded that there is a need for greater awareness by healthcare workers of the difficulties faced by this group of people and the culture and past experiences affecting their behaviour. Wilson et al. (2010) emphasised the requirement for those involved in smoking cessation to be able to provide alternative behaviours to take the place of smoking. The findings of both studies are relevant to the present study in that they indicate a discrepancy in the perceptions of patients and healthcare professionals regarding the way in which this particular psychosocial need is being met. However, it would have been advantageous for these studies to also explore the experiences of healthcare workers responsible for carrying out smoking cessation interventions in order to examine their perceptions.

When Bailey et al. (2009) explored the narratives of people with COPD; they found a variation in their explanations for the perceived cause of their illness, in that some of the participants in their study believed that the cause of their illness was more complex than simply having been a cigarette smoker. They concluded that there was a need for clinicians to consider these individual perceptions of causality, rather than concentrating on the 'fact' that COPD is caused by cigarette smoking, if they are to provide appropriate, individualised care for patients with COPD (Bailey et al., 2009).

Other causative factors: Before examining the way in which the symptoms of COPD affect the everyday lives of those who live with this condition, it is relevant to consider some recent studies that have looked at air pollution as a contributory factor in the onset, or development of respiratory ill health. This is an important factor in the day-to-day experience of those who live with COPD.

Although it is acknowledged that cigarette smoking is the major cause of COPD, two recent studies have put the emphasis on the effect of air pollution on respiratory health. Andersen et al. (2011) looked specifically at the effect of traffic pollution on the development of COPD in their study that was carried out with 57053 participants in Denmark. They examined existing databases and assessed the amount of traffic pollution people had been exposed to in their home locations.

Andersen et al (2011) used models to determine outdoor levels of nitrogen dioxide (NO₂) at the residential location of the individuals and included a measure of nitrogen

oxides (NO_x). In addition, the study also included a measure of traffic load (defined as the total number of kilometres driven by vehicles within a 200m radius). This study had a large cohort and estimated exposure to air pollution over a period of 35 years. This would suggest a powerful study. However, as an outcome measure, Andersen et al. (2011) used the first-ever hospital admission for COPD which, although reliable in terms of obtaining data, was an indirect measure of diagnosis of COPD. This means that the data could not be used to find a direct association between traffic pollution and development of COPD, but did find a link. They found a positive association between COPD and accumulated exposure to traffic related air pollution (Andersen et al., 2011).

It should be noted that the effects detected by Andersen et al. (2011) were weak or borderline and may not be replicated in further studies. However, despite its strengths and weaknesses described above, the study has highlighted the possibility of an alternative cause for the development of COPD, other than cigarette smoking, in some people.

In another similar study, a review of the data was carried out by researchers in Hong Kong, who looked at the influence of both outdoor air pollution (ambient and from traffic fumes) and indoor air pollution (second-hand smoking and biomass fuel combustion) on the development of COPD (Ko & Hui, 2012). That paper, however, did not clearly define the search strategy employed and only one table was produced showing some examples of the association between outdoor air pollution and hospital admissions for acute exacerbations of COPD.

In their conclusion, Ko and Hui (2012) stated that there was insufficient evidence to prove a causal link between air pollution (outdoor and indoor) with the development of COPD and added little to the existing conclusions published in the individual papers included in their review. However, despite not finding a causal link between outdoor and indoor air pollution with the development of COPD, the authors of this paper did acknowledge that measures taken to improve air pollution outdoors and to improve ventilation where biomass fuels are used, have shown health benefits. Ko and Hui's (2012) study reached the important conclusion that more work needs to be done in the public health sector to improve air quality outdoors and to take measures to

reduce the risk factors for those exposed to indoor air pollution resulting from the use of biomass fuels.

People who have COPD experience a number of symptoms that affect their ability to carry out their activities of daily living. These symptoms vary in number and severity between people and will also increase in severity as the illness progresses. The next section of this chapter will explore the recent literature concerned with the symptoms of COPD that affect the lived experience of people with this condition.

2.1.2 Literature concerning the symptoms of COPD

In exploring the lived experience of people with COPD, it is necessary to understand the symptoms that they experience on a day-to-day basis and how these affect their quality of life and psychological well-being. Recent studies have looked at different aspects of the lives of people with COPD and other long-term conditions. These studies are particularly relevant as the care of older people with long-term conditions is an increasingly important challenge to be faced by the UK healthcare system.

The most prominent symptom of COPD is breathlessness but, in addition, patients experience further symptoms such as cough, poor exercise tolerance, depression, anxiety, fatigue, sleeping difficulties and pain (Borge et al, 2010). The combination of these, and potentially other symptoms, and the fact that the symptom burden increases as the disease progresses with time, means that the experience of living with COPD can lead to impaired physical function and reduced quality of life (Blinderman et al., 2009). This multiplicity of symptoms characterizes COPD as a condition that requires a range of treatment and support to meet the physical and psychosocial needs of those who live with COPD.

As with other long-term conditions, such as osteoarthritis, coronary heart disease or type 2 diabetes for example, COPD is a condition that mainly affects older people who will be experiencing both the symptoms of a long-term condition alongside the process of ageing. This presents a challenge in distinguishing the effects of the long-term condition from those of the ageing process and can result in the assumption

that any difficulties experienced by older people are related to their age rather than their existing medical condition (Hewitt-Taylor et al., 2013). People who have been previously diagnosed with a long-term condition may have an advantage over those who are diagnosed later in life in that they have knowledge and strategies in coping with illness, which they can use as transferable skills, to help them cope with the ageing process (Hewitt-Taylor et al., 2013).

However, Hewitt-Taylor et al. (2013) found, in their study of five men and two women aged over 65 years with pre-existing long-term conditions, that additional age-related problems could affect people's management of their illness and that generational values may make them less likely to seek practical assistance where necessary. This can be a further challenge to meeting the psychosocial needs of older people with long-term conditions. Similarly, Roy and Giddings (2011), in their study exploring the experiences of nine older women in New Zealand who were living with previously diagnosed long-term conditions, concluded that health professionals should be aware that age-related assumptions about patients by staff might overshadow a patient's chronic illness.

Borge et al. (2010) examined the association between various symptoms experienced by people with COPD. They carried out lung function tests on 154 patients with COPD, who then completed a range of questionnaires covering demographic variables, experience of pain, anxiety and depression, fatigue, sleep disturbances and quality of life. From their findings, they recommended that those who treat people with COPD should have an increased focus on multiple symptoms (Borge et al., 2010). The study was a quantitative study and involved data from a number of self-report measures but the response rate was low (40%) and participants were identified from medical records, which may mean that some borderline cases of COPD may have been included. It would be of value to have obtained some qualitative data in addition, in order to obtain a deeper understanding of the experience of living with the symptoms of COPD.

Similarly, routine treatment for COPD tends to concentrate largely on the control of breathlessness and pain is not generally considered one of the primary symptoms although in a later study carried out by Borge et al. (2011), 72% of their sample of

COPD patients marked down pain in some area on a body map. Pain may be under recognized as a symptom and can represent a hidden burden for those with COPD (Borge et al., 2011). The experience of pain can be compared to that of breathlessness in that it is regarded as a biopsychosocial phenomenon and is affected by both clinical and demographic variables (Borge et al., 2011). In this study, using data from self-report measures, they found that this experience of pain reduced disease-specific quality of life and recommended that this should be highlighted in both clinical situations and in research (Borge et al., 2011). However, the experience of pain is multifaceted and there is some overlap between pain and breathlessness, which may be difficult to explain within the restrictions of a questionnaire response. Further research, using data from both quantitative and qualitative sources may give a better understanding of how a combination of symptoms are experienced in patients with COPD.

The avoidance of exercise-induced breathlessness in COPD and subsequent immobility leads to physical deconditioning (Bentsen et al., 2010). Therefore, one important factor in the treatment of COPD is to encourage an increase in physical activity as this has been shown to decrease severity of breathlessness and improve both muscle function and quality of life (Hartman et al, 2013). In their study with COPD patients who had mild to very severe COPD, Hartman et al. (2013) found that both physical and psychosocial factors were associated with physical activity in COPD. This, again, emphasises the need for patients with COPD to receive support for their psychosocial needs in addition to clinical treatment for their symptoms.

In addition to studies that have explored the patients' perceptions of their illness, research has been carried out into the perceptions of healthcare workers regarding long-term ill health. Yen et al. (2010) explored health professionals' attitudes to patients' perceptions of health issues in two urban areas of Australia. This was a qualitative study in which healthcare professionals took part in focus groups where they explored responses to patients' experiences of chronic illness (COPD, diabetes and congestive heart failure (CHF)), using data obtained in an earlier study. An important finding from this study was that, although healthcare professionals held many perspectives that were similar to those of the patients living with long-term

conditions, there were some differences in perceptions between the two groups. In terms of patient compliance with treatment, both groups identified social and economic issues as key elements (Yen et al., 2010). The other main issue that emerged was that of fragmented care and the inherent problems that come with a healthcare system that does not provide collaborative care, where mental health care is integrated into primary care (Yen et al., 2010).

Yen et al.'s (2010) study is important in that it explores the views of patients with long-term conditions and those of the people who care for them in the healthcare system. However, this study was conducted in Australia where the organization of the healthcare system and the challenges facing people with conditions such as COPD are different from those in the UK. For example, concerning economic considerations, some patients in the Australian study had problems of being unable to afford to pay for their prescribed medication whereas, in the UK, many patients with COPD are exempt from prescription charges because of their age. Although, as with Halding et al.'s (2010) study, the participant group was small, Yen et al.'s (2010) study highlights the need for the experiences of patients to be included in policy making if the healthcare system is to provide better outcomes for those with chronic illnesses. It would therefore be of value to carry out a study in the UK that explores the experiences of both patients and healthcare professionals.

In order to conduct a study which aims to explore the affect that the symptoms of COPD have on peoples' lived experience, it is necessary to understand, not only the individual symptoms, but also the challenges that arise from experiencing symptoms of a number of conditions at one time. The next section of the chapter therefore reviews the literature around comorbidities in people with COPD.

2.1.3 Literature concerning COPD and comorbidities

Many people with COPD experience multimorbidity, i.e. *"the co-existence of two or more chronic conditions, where one is not necessarily more central than the others"* (Boyd & Fortin, 2010, p.453). This situation increases their health burden and can also lead to difficulties caused by polypharmacy and the inherent problems in

attending appointments with different health professionals. In a healthcare system designed around specialist treatment for different conditions, patients may find that they experience repetition of tests and information or may be given conflicting advice by different specialists (Boyd & Fortin, 2010).

Recent studies have looked at the situation regarding multimorbidity and the accompanying challenges. Barnett et al. (2012) extracted data from a database of patients in over 300 medical practices in Scotland and found that there was a strong association between multimorbidity and age, but that young and middle-aged people in deprived areas have approximately the same incidence of multimorbidity as people ten to fifteen years older living in affluent areas. They also found that mental health disorders were more prevalent in those who had increasing numbers of physical conditions and this situation is found to be associated with poor physical and mental health outcomes (Boyd & Fortin, 2010). The requirement for the healthcare system to address these psychosocial needs is a factor relevant to the present study.

Bower et al. (2011) took a different approach to examining the subject of multimorbidity when they carried out a qualitative study to explore the perceptions of GPs and practice nurses who treat patients with more than one long-term condition. They found that many primary care services for patients with long-term conditions take the form of condition-specific clinics designed to fulfil the terms of the Quality and Outcomes Framework (QOF) (QOF, Department of Health, 2003) with limited evidence of service organization designed to meet the needs of those with multimorbidity (Bower et al., 2011). This study provided an insight into the perceptions of those healthcare professionals who treat people with long-term conditions in primary care and, in particular, how QOF has defined the structure of this care. Bower et al. (2011) suggest that this has led to a conflict between patient-defined needs and professionally defined needs that limits the professionals' ability to be able to fulfil the requirements of patients with multimorbidity.

Bower et al.'s (2011) findings were based solely on data from a volunteer group of healthcare professionals from one area of the UK and, in addition, there is no evidence that their accounts related strongly to actual behaviours. However, both Boyd and Fortin (2010) and Bower et al. (2011) concluded that there is a need for

changes in the healthcare system in order to fulfil the physical and psychosocial needs of patients with multimorbidity. People with multimorbidity require a patient- and family-centred approach to care (Boyd & Fortin, 2010) with a programme of care-planning, sensitive to their individual needs, and agreement between professional and patient would ease the treatment burden for this group of patients (Bower et al, 2011).

Dury (2015) talks about the potential benefits of providing integrated care for the many people with long-term illnesses who also have comorbid mental health conditions. Embedding the concept of cross-boundary care into the present system of health and social care would improve outcomes for those with both physical and psychological ill health (Dury, 2015). The following section of the chapter explores the literature concerned with the interaction of physical and psychological symptoms in COPD and how people with the condition perceive this interaction.

2.1.4 Literature concerning the interaction between physical and psychological symptoms in COPD

The interaction between physical and psychological symptoms in long-term conditions is an important challenge to individuals living with COPD and to those who care for them. This is most apparent in the experience of breathlessness. Breathlessness (dyspnoea) is the most common physical symptom experienced by people with COPD (Pitta et al., 2005). Dyspnoea has been defined as *“a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity”* (Parshall et al., 2012, p.436) and it is described as *“a complex, multidimensional phenomenon with interrelated physiological, psychological and sociological components”* (Parshall et al., 2012, p.437). This symptom can be described as similar to pain in that it is influenced and shaped by emotions and psychological, social and environmental experiences (Carrieri-Kohlman et al., 2010). These emotional and psychological factors are apparent when patients experience a fear of breathlessness, which often results in avoidance of the physical activities that causes this symptom. As described by Bentsen et al. (2010), this leads to

deconditioning and influences COPD outcomes. It has been shown that anxiety and dyspnoea-related fear have a negative effect on quality of life, functional status and exercise capacity in those with COPD (Janssens et al., 2011).

Al-Gamal (2014) carried out a study looking at the impact of breathlessness on Jordanian patients with COPD and their partners' perception of the patients' breathlessness. It was found that patients with a high level of breathlessness experienced a higher level of psychological distress and that their partners also reported significant levels of anxiety and depression (Al-Gamal, 2014). This quantitative study relied on self-report data and included no objective measure of breathlessness. However, it would be of interest to carry out a study in the UK that included the perceptions of caregivers, as they are often important decision-makers in terms of seeking medical help for the patient. Further findings of this nature may be valuable in supporting the inclusion of family and carers in interventions for COPD patients, such as pulmonary rehabilitation.

Rates of anxiety and depression are known to be higher in patients with COPD than in the general population. Prevalence rates for depression of 19-40% and anxiety 28-36% have been recorded (Di Marco et al., 2006; Yohannes et al., 2006). These psychological comorbidities have been found to significantly increase physical disability, morbidity, comorbidity and use of the healthcare system as well as interfering with compliance with medical treatment (Maurer et al., 2008).

Eisner et al., (2010) found that, in patients with COPD, anxiety was related to poorer health outcomes in terms of exercise performance and functional limitations. In addition, it was found that those with COPD and anxiety had a higher risk of exacerbation (Eisner et al., 2010). This study was conducted with a large cohort of COPD patients (n=1202) and a matched control group using a number of validated measures to determine COPD severity. Spirometry was used to measure respiratory impairment but breathlessness was measured using the self-report MRC dyspnoea scale. The HADS anxiety measure, a self-report scale, was used to measure anxiety. Although the HADS is a valid and reliable measure for anxiety, it is not a clinical diagnosis and the authors acknowledged that the relationship between COPD and anxiety is a complex one, however the study is important in that it highlights the need

for further investigation into the effectiveness of screening and treatment for anxiety in patients with COPD.

A number of studies have been carried out concerning the possible relationship between dyspnoea and psychological comorbidities in COPD, particularly anxiety and panic. Panic attacks and/or panic disorder are highly prevalent in COPD (Livermore et al., 2012). Clark's (1986) cognitive model of panic (see Fig.2.1, p.57) is the most widely accepted theory of panic in the last thirty years. According to this model, catastrophic misinterpretations of bodily symptoms, such as shortness of breath, increase arousal, which then creates a positive feedback loop resulting in a panic attack. For people with COPD, breathlessness is a major symptom of their condition that threatens their most basic physical requirement and, as such, is open to catastrophic interpretation (Livermore et al., 2010). In addition, anxiety leads to an increase in respiratory rate, which will then increase the symptoms of dyspnoea in people with COPD and, according to Clark's model, will lead to the cycle of panic illustrated in Fig 2.1.

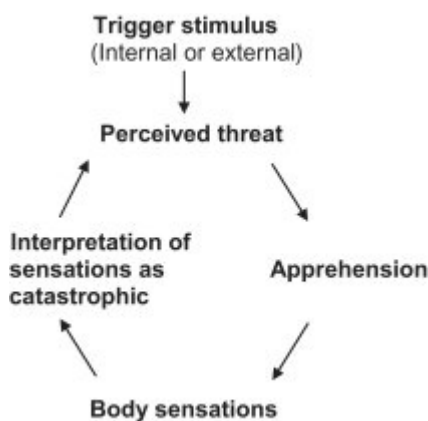


Fig.2.1 Clark's model of the suggested sequence of events in a panic attack. From Clark (1986, p. 463).

Hallas et al. (2012) carried out a qualitative study in which they interviewed twelve people with chronic respiratory illness with specific reference to breathlessness and panic. Their findings supported the cognitive model of anxiety (Clark, 1986) and its use in understanding panic experienced by respiratory patients. The data was

analysed using Interpretative Phenomenological Analysis (IPA) and 'perceived control over the disease, symptoms and panic' emerged as the core theme (Hallas et al., 2012). Although a qualitative study, with a self-selecting sample of this size, does not claim to be generalizable, it is relevant to the present study in that the data explores the lived experience of people with respiratory problems. In addition, it contributes to the understanding of patients' underlying beliefs about living with respiratory illness and the importance of the cognitive contribution to panic and breathlessness.

Cognitive behavioural therapy is often used in otherwise healthy people to decrease catastrophic beliefs about symptoms and therefore break the cycle of events. Livermore et al's (2012) findings also indicated support for the cognitive model of panic. Furthermore, they conclude that early screening for psychological problems in people with COPD and early intervention with cognitive behavioural therapy would be beneficial (Livermore et al., 2012).

Several recent studies have examined the efficacy of CBT in treating anxiety and panic in COPD patients. Livermore et al. (2010) administered a course of four, individually conducted, one-hour sessions of CBT to patients with COPD. This intervention was specifically designed to address panic-spectrum psychopathology (panic attacks to panic disorder) and outcomes included a reduction in the number of panic attacks and a decrease in hospital admissions compared with the group receiving regular care (Livermore et al., 2010). The study was carried out with a small sample size (n=21 for the CBT group and n=20 for the control group) and neither group was blind to their treatment condition, therefore further studies would be required to confirm these findings. Hynninen et al. (2010) reported similar findings in a randomized controlled trial carried out with COPD patients in Norway. Although this study did not look at CBT as a treatment for panic disorder, it was found that CBT could provide symptom relief for COPD patients with clinically significant anxiety and depression and the authors recommended that mental health care should be integrated into the overall treatment regime for COPD (Hynninen et al., 2010). Although the randomized controlled trial is a rigorous method, the sample size was again small (n=25 in the CBT group) and the outcome measures were self-report rather than a clinical

diagnosis of anxiety or depression. In addition, the participants who agreed to take part after the initial interview may have been more responsive to group treatment than those who declined.

Heslop (2014), in addition to exercise and pulmonary rehabilitation, also recommends CBT to relieve symptoms of anxiety in patients with COPD and Barker et al. (2014) carried out an intervention in which community matrons, working with people with COPD, were trained in CBT skills. Although there was some good feedback in that the nurses valued the sessions, there were differing experiences when they came to put their skills into practice. Some found lack of time in consultations to be a barrier while others found that some patients were unwilling to engage with the treatment (Barker et al., 2014).

Barrera et al., 2014 indicates that, in order for CBT to be an effective therapy, patients are required to undergo interoceptive exposure to avoided situations, in which the physical sensations of a panic attack, such as hyperventilation, are induced in order to remove the patient's conditioned response. This aims to remove the fear of a panic attack happening whenever the person experiences a stimulus that has become a precursor to an attack. However, for people with COPD, due to the nature of the condition, this needs to be handled carefully in consultation with the patient's respiratory consultant (Livermore et al., 2010). The following part of the chapter will review recent literature concerned with the ways in which the healthcare system meets both the physical and psychosocial needs of COPD patients.

2.1.5 Literature around how the healthcare system meets the psychosocial needs of COPD patients

The present study aims to explore how the healthcare system is meeting the psychosocial needs of patients with COPD. Healthcare encounters for this patient group can be in primary care, as routine reviews with a practice nurse or acute consultations with a GP, in secondary care at outpatient clinics or as an inpatient during exacerbations of the disease. In addition, they may be able to attend a course

of pulmonary rehabilitation or receive psychological treatment for anxiety or depression.

The existing literature around primary care consultations has stressed the need for personalized care in the healthcare system. This would mean that the clinician could take account of the patient's full range of medical and psychosocial needs, including health, personal, social, economic, educational, mental health, ethnic and cultural background, which can impact on the well-being of the individual (Department of Health, 2006). Linked to this model, is the concept of 'patient-centredness' i.e. looking at illness with a broader, biopsychosocial perspective and understanding the patient's unique experience of their condition (Mead & Bower, 2000).

Medical care of people with COPD has improved in recent years with mortality in hospital falling from 7.8% in 2008 to 4.3% in 2014 and the median length of inpatient care decreasing from five days to four, with more patients leaving hospital early on supported discharge schemes (Wise, 2015). However, the psychosocial needs of the patients may still remain unmet. Disler et al. (2014) in a review of the literature concluded that, despite improvements in medication and treatment, people with COPD still have ongoing needs that need to be addressed. According to the Oxford English Dictionary (OED), 'psychosocial' is defined as 'of or relating to the interrelation of social factors and individual thought and behaviour' (OED, 2015). Psychosocial needs, therefore pertain to the mental, emotional, social and spiritual health of individuals. Examples of psychosocial needs in people with COPD may therefore include those relating to the loss of capabilities, increased dependence on others, social isolation and loss of hope (Disler et al., 2014).

COPD patients who experience care in an intensive care unit with an exacerbation of their condition have reported that they experienced a lack of understanding from healthcare workers with respect to their emotional needs and some expressed the view that they were made to feel that the uncomfortable treatment was a punishment for a self-induced disease (Torheim and Kvangarsnes, 2014).

However, as the majority of routine encounters for the care of long-term conditions take place in GP practices it is important to look at recent changes in the

management of these chronic illnesses. In 2004, the Quality and Outcomes (QOF) framework was introduced into primary care in the UK. This incentivizes professional activity and financially rewards GP practices for demonstrating that they have achieved clinical quality indicators (Department of Health, 2003). This has led to the introduction of a system of chronic disease management in primary care whereby patients with long-term conditions are invited for regular reviews, usually with a practice nurse, to monitor their progress. The introduction of QOF may be said to have led to the requirement for healthcare practitioners to follow inflexible guidelines in order to achieve targets, and hence remuneration, which may have resulted in unintended consequences, such as reduced continuity of care (Cocksedge et al., 2011). Further concerns about the introduction of QOF include the possibility that clinicians may concentrate on incentivized conditions at the expense of other illnesses (Doran et al., 2011).

There have also been concerns that incentive schemes, such as QOF, lead to more doctor-centric consultations in which GPs and nurses attend to prompts delivered by computer systems rather than cues from the patients (Jamie, 2013). Chew-Graham et al. (2013) carried out a longitudinal qualitative study exploring patients' experiences of these review consultations in primary care in the UK. Chew-Graham et al. (2013) collected a rich data set for this study, including audio-recordings of consultations of primary care practitioners and subsequent interviews with the same patients and practitioners using tape-assisted recall. Patient participants were followed up weekly by telephone for a period of three months, after which a further interview was conducted. Findings from this study indicated that the focus of the review appointments was on the biomedical aspects of the illness i.e. those that were assessed in order to fulfil the requirements of QOF. Furthermore, some patients reported that other concerns were ignored by the practitioner and that they had left the consultation with unmet biomedical, informational and emotional needs (Chew-Graham et al., 2013).

Upton et al. (2010) looked specifically at the assessment of psychosocial problems in patients with COPD in primary care in the UK. They too found that nurses focussed on objective tasks and suggested that this may be detrimental to their assessment of

patients' psychosocial needs (Upton et al., 2010). Unlike Chew-Graham et al.'s (2013) study, this was a quantitative study using self-reported questionnaires and therefore, of those nurses who did assess psychosocial problems, there was no indication of how well this was carried out or whether the frequency of this activity was recalled accurately (Upton et al., 2010). They concluded that there was a need to develop appropriate validated tools to encourage holistic care in patients with COPD as their disease progresses and to incorporate psychosocial assessment scales in the QOF computer templates used by the nurses (Upton et al., 2010).

Another recent study in the UK has recommended the inclusion of a psychological intervention as part of routine reviews for COPD patients (Hardy et al., 2014). In this study, nurses who carried out routine reviews with COPD patients in primary care were trained in how to screen for anxiety and depression and to offer psychosocial education using a motivational interviewing approach. They found that this helped patients to feel more motivated to manage their COPD and more inclined to take up an offer of PR (Hardy et al., 2014). This is important because it has been shown that PR can reduce symptoms of anxiety and depression in patients with mild to moderate COPD (Coventry & Hind, 2007).

One of the reasons why primary care practitioners report that they are unable to assess or treat problems such as anxiety or depression in routine appointments is the limited amount of time available to them (Hunter et al., 2014). Bearing this in mind, an intervention was carried out in North-West England whereby two Liaison Health Workers (LHWs) were placed in GP practices to assist the practice nurses with meeting the psychosocial needs of their COPD patients. Langer et al. (2014) carried out a qualitative study evaluating how these LHWs were integrated into the primary care system and exploring the experiences of the patients who received this intervention. Patients were surprised to find that the LHWs supported them in a holistic way and were attentive to their emotional needs as well as their physical ones and reported that they felt empowered and motivated because of the intervention (Langer et al, 2014).

However, although healthcare professionals were also positive about the work done by the LHWs, they regarded them as peripheral to the primary care team and, despite

this being an intervention designed to care for patients in an integrated, holistic way, the work of the LHWs remained a part of a fragmented system of healthcare (Langer et al., 2014). Some patients were unwilling to take up the offer of intervention, but there was little opportunity within the study to understand why this was the case, or to explore the reasons why some withdrew before completion. In addition, the follow-up period was too short to establish how long the motivational benefits may have lasted. Finally, this was a relatively small study in that only two LHWs were trained and placed within three GP practices. However, the study indicates that elements of their work could be incorporated into the existing healthcare regimes within primary care to the benefit of patients and the healthcare system (Langer et al., 2014).

One of the ways of meeting the psychosocial needs of patients with long-term conditions is to support them with making changes in their lifestyle and behaviour. Hunter et al. (2014) conducted a qualitative study to examine how behaviour change is approached in primary care routine consultations. Although healthcare practitioners are aware that behaviour change with respect to smoking cessation and increase in physical activity can be beneficial for COPD patients, it has been shown that this is rarely brought up as a topic in consultations (Hunter et al., 2014). Several reasons have been suggested for this including, time constraints, patients' lack of motivation and practitioners' lack of training or confidence. However, some practitioners believed that promoting behaviour change might damage the doctor-patient relationship without resulting in behaviour change (Hunter et al., 2014).

Although the present study is examining how the healthcare system is meeting the psychosocial needs of people with COPD, it is also possible that community groups and the voluntary sector can be an additional source of support. As an example, a research group in the North-West of England held a series of focus groups and interviews with members of local community groups to establish an intervention designed to link people with long-term conditions to community support in their area (Blickem et al., 2013). The data they obtained indicated that interventions should be tailored to patients' individual psychosocial needs and be relevant to their everyday lives but the authors acknowledged that this would take a shift in health provision

away from individuals towards network support and social engagement (Blickem et al., 2013).

People with long-term conditions, such as COPD, have varying experiences of treatment and support. This may be due to influences such as the severity of their condition or the availability of services in the area in which they live. However, how they engage with services may also be a manifestation of their perceived locus of control and the next section of this chapter will discuss this concept and the recent literature around it.

2.1.6 Literature concerning locus of control

The way in which people respond to illness and treatment can be explained in terms of their perceived locus of control. The original concept of locus of control was introduced by Rotter (1966) to describe the perceived degree of control a person has over events that affect them. Those with an internal locus of control believe that events are within their own control whereas those with an external locus of control believe that what happens to them is a result of the actions of powerful others or chance. Locus of control was applied to the area of health by Wallston et al. (1978) who compiled a scale to measure its dimensionality. Recent studies have had differing results when exploring the relationship between illness and locus of control. Cano-Garcia et al. (2013) found inconsistent evidence linking locus of control with experience of headaches and chronic pain but Zampieri and de Souza (2011) found a positive correlation between external locus of control and depression and quality of life scores in people with Parkinson's disease. Schutzler and Witt (2014) explored the relationship between locus of control and use of complementary and alternative medicine (CAM) and found that those with a higher use of CAM showed higher internal locus of control. However, it was unclear whether these people used CAM more because they had a higher internal locus of control or whether the use of CAM increased their level of internal locus of control.

Literature of relevance to the present study has indicated that older people with poor health are more likely to have an external locus of control and, in particular, that

powerful others largely influence their health (Jacobs-Lawson et al., 2011). However, Jacobs-Lawson et al's (2011) study did not take into account psychosocial variables such as anxiety, depression and social support, which may have a relation to locus of control. In addition, it has been shown that patients with complex medical problems and multimorbidity tend to exhibit a more external locus of control and regard themselves as having little control over their situation (Henninger et al., 2012). In their conclusion, Henninger et al (2012) suggest that this external locus of control may interfere with the patients' ability to self-manage their healthcare and that this should be taken into account by healthcare professionals when deciding upon appropriate treatments for this patient group.

Furthermore, a comparison of the perceptions of nurses and patients with regards to health locus of control also indicated that patients believed that that healthcare professional have the highest control over their health outcomes, whereas nurses had a lower perception of this situation (Hamdan-Mansour et al., 2014). Again, this is something that will need to be taken into consideration if an agreed healthcare plan is to be drawn up between patients and healthcare professionals.

The following section of the chapter is concerned with literature around the experience of pulmonary rehabilitation. Pulmonary rehabilitation is an intervention designed to support people with COPD through a programme of education, exercise and social interaction. It is a recommended non-pharmaceutical treatment for COPD but may not, at present, be available to all who could benefit from it.

2.1.7 Literature concerning pulmonary rehabilitation (PR)

Pulmonary rehabilitation (PR) is a programme of exercise training and education that is recommended as one of the main non-pharmaceutical treatments for COPD (GOLD, 2013). It has been shown to be beneficial in managing breathlessness, improving exercise capacity and controlling progress of the disease (Lacasse et al., 2009). Of significant importance to the present study is the recommendation that psychosocial interventions be included in the PR programme (NCGC, 2010). According to Spruit et al. (2013) in their joint statement of the American Thoracic

Society (ATS) and the European Respiratory Society, anxiety and depression are prevalent in people who attend PR and their symptoms can be alleviated by experiencing the programme.

Recent studies have looked at PR and its outcomes for COPD patients. For example, Bentsen et al. (2010) carried out an exploratory study in Norway with COPD patients who attended a six-week outpatient course of PR. These participants reported significantly improved psychological and social functioning after completion of the course. Furthermore, this effect was greatest in patients who had a higher level of self-efficacy at baseline (Bentsen et al., 2010). Self-efficacy is a measure of how much confidence individuals have in their ability to carry out actions in order to deal with a situation and may be said to be related to locus of control. Based on their findings, Bentsen et al. (2010) suggest that, in addition to the exercise and education elements of the programme, PR should include intervention to improve patients' perceived self-efficacy, in order for them to gain the maximum benefit from the course. This however would require further training for the healthcare professionals involved in delivering the PR courses and more research would be required to support this study before adding self-efficacy support to the existing elements of the programme.

Although the current literature is generally in agreement about the beneficial effects of PR, a study by Bratas et al. (2012) found that there was a decrease in effect in the months following completion of the course. A four-week inpatient course of PR was shown to improve health related quality of life and psychological health in patients with mild to very severe COPD; however, these effects had reverted after six months (Bratas et al., 2012). The study conducted by Bratas et al. (2012) also took place in Norway and, although the PR course contained similar elements of exercise and patient education, it was an inpatient course and very different from the out-patient course, held twice weekly for eight weeks, attended by some of the participants in the present study. It is therefore not possible to make any meaningful comparisons with the experiences of participants in the present study.

A qualitative interview study of COPD patients attending an outpatient course of PR in a Norwegian hospital found that they experienced both physical and psychological benefits from the programme. Participants reported that they had a better

awareness of how they could improve their condition, as well as increased confidence and coping skills (Halding & Heggdal, 2012). However, this group of patients also reported a need for ongoing professional and peer support during the year after PR in order to maintain this level of confidence and self-management skills (Halding & Heggdal, 2012). This finding can be related to the study by Bratas et al. (2012), in that maintenance of the positive effects of PR required support and input by professionals and peers. Halding and Heggdal (2012) acknowledged that there are new challenges to be faced when individuals have completed a course of PR and need to put the skills they have acquired into practice as part of their everyday lived experience of COPD.

The findings from these studies conducted in Norway are supportive of PR as an intervention for people with COPD and indicate that it has a beneficial role in meeting some of the psychosocial needs of the patients (Bentsen et al., 2010; Bratas et al., 2012; Halding & Heggdal, 2012). However, the suggested follow-up support, whether it is from family, carers or healthcare professionals would require training and resources which may not be available in the present UK healthcare system. The majority of PR programmes that are available to people in the UK are run as group interventions and the sense of 'belonging' is an important factor in the patients' experiences of commonality, shared understanding and fellowship found in these groups (Halding et al., 2010).

The findings from a study carried out in the UK by Hogg et al. (2012) using focus groups of people who had attended PR either with, or without, supported follow-up programmes, agree with Bentsen et al. (2010) that confidence is an important determinant of participation in physical activity in COPD patients. They also suggest that support from peers and healthcare professionals is required for individuals to continue with physical activity after a course of PR. Hogg et al. (2012) recommend that health services should work in collaboration with the voluntary sector and local authorities in order to achieve a support network for these individuals. The use of these agencies in this way would alleviate some of the pressure on the healthcare system and patients would benefit from the facilities offered by local authorities and the knowledge and experience of members of support groups, such as Breathe Easy

(a support group for people with respiratory illness, affiliated to the British Lung Foundation). Data from the present study will include accounts of peoples' experiences of gaining ongoing support by using local facilities for taking part in physical activity or by joining a Breathe Easy group.

One of the limitations of studies where people have to travel to attend PR groups is that this excludes those whose illness makes it difficult for them to drive or who have difficulty in travelling on public transport. Keating et al. (2011) interviewed COPD patients either who had declined to take up the offer of a place on a PR course or who had failed to complete the course, in order to examine the perceived barriers to taking part in the programme. They found that lack of perceived benefit was the reason given by eleven of the nineteen patients who chose not to attend and suggested that the potential benefits of PR could be communicated in a meaningful way by others with COPD who have personal experience of the programme (Keating et al., 2011). More than half the participants gave transport difficulties as a barrier to attending PR (Keating et al., 2011). This study was carried out in Australia where the cost of transport and the distance required to reach a venue may be greater than in the UK. However, the problems cited by the patients such as availability of public transport and having to rely on friends or relatives for assistance could be equally relevant to COPD patients in the UK.

Holland and Hill (2011) in their review of recent literature around PR also found that transport difficulties were a barrier to attendance and they concluded that PR should be more flexible in order to include COPD patients who are unable to benefit from the present system. Home based PR could be a possible way of enabling those who cannot travel to be able to benefit from the programme (Spruit et al, 2013). However, this has drawbacks such as being expensive, labour intensive and lacking in peer support (Holland & Hill, 2011). Jacome and Marques (2014) carried out a review of the evidence to examine whether PR could be of benefit to those with mild COPD and concluded that there was insufficient evidence yet to support the extension of the PR programme to this patient group. However, the joint statement of the ATS and ERS in 2013 stated that those with mild COPD could derive improvements in their

symptoms, exercise tolerance and QOL in a similar way to those with more severe COPD (Spruit et al., 2013).

One of the intended outcomes for those who have attended a course of PR is that they will have attained further knowledge about their illness and about how changes in lifestyle and exercise are able to improve their quality of life. This knowledge and experience may provide patients with skills to enable them to self-manage their condition more easily and have greater control over their symptoms. Literature that has explored the concept of self-management and its relevance to long-term conditions, such as COPD, will be discussed in the next part of the chapter.

2.1.8 Literature concerning self-management

According to the joint statement from the American Thoracic Society (ATS) and European Respiratory Society (ERS) (2013), one of the core components of PR is patient education, which is designed primarily to teach self-management skills. These skills lead to illness control through behaviour modification and increase self-efficacy with the goals of improving health status, quality of life, use of healthcare and survival (Spruit et al., 2013). Janssen and Engelberg (2010) reviewed the literature around the teaching of self-efficacy and self-management skills in PR and concluded that it was important to tailor these educational programmes to the individual needs and abilities of COPD patients, in order for them to be most effective in improving QOL.

The terms self-care and self-management are sometimes used interchangeably but according to Jones et al. (2011), who carried out a review of the literature, there are definitions that distinguish between the two concepts. According to the Department of Health (2005), self-care is the care that individuals take of their own health and well-being as part of their daily lives. It includes the actions people take to maintain good physical and mental health and to meet their psychological and social needs (Department of Health, 2005). Self-management in chronic disease can be regarded as disease specific and has been defined as *'the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes*

inherent in living with a chronic condition' (Barlow et al., 2002, p. 366). For the purpose of this account, the term self-management would be most appropriate.

For people with long-term conditions, there is an increasing focus on self-management in the healthcare system but the concept is not always understood or accepted by patients themselves. In a qualitative study of people with chronic respiratory illness, Kielmann et al. (2010) found that some patients appreciated the opportunity to accept more responsibility for their own care whereas others felt abandoned by healthcare professionals. One important finding from the study was that patients' need for access to professional care varied according to whether their symptoms were stable or they were in an acutely unwell stage. It is therefore necessary for the boundary between self-management and professional care to be flexible and for healthcare professionals to be available when required, either face-to-face or by telephone or email (Kielmann et al., 2010). It was also apparent that people who self-manage value emotional and practical support from carers, family members and friends as well as information from self-help groups such as Breathe Easy or from the internet (Kielmann et al., 2010).

As self-management requires some shift in decision-making focus from professional to patient, it follows that there are major implications for the healthcare system (Lawn et al., 2011). Although it is intended to be empowering for patients, there are some who are unable or unwilling to take on this responsibility and prefer to continue with the concept of clinician as expert. When writing about self-management for people with long-term conditions, Lawn et al. (2011) conclude that it is important for healthcare professionals to reflect on the meaning of self-management in this context to avoid assumptions that may stigmatise or alienate patients, particularly those with complex needs. In their paper, Lawn et al. (2011) concentrate on the Australian healthcare system rather than the UK context that is relevant to the present study. However, despite structural differences in healthcare system and management between Australia and the UK, the requirement to be aware of the patient's needs and ability to self-manage applies equally to both.

Simpson and Jones (2013) collected both quantitative and qualitative questionnaire data concerning self-management from primary care COPD patients in Scotland, and

found that there was an association between high levels of self-efficacy and lower levels of anxiety and depression in this group. Participants were asked to record on the questionnaire, what helped or hindered them in managing their COPD and what suggestions they had to improve the self-management support they receive. This qualitative data suggested that self-management support was needed to help COPD patients to cope more effectively with the psychological effects of their condition (Simpson & Jones, 2013). The response rate for this study was low at 19.2% and an interview or focus group method would have provided the study with richer data than that which could be given in a limited space on a questionnaire. However, the study again highlights the need for appropriate professional support for patients involved in self-management of a long-term condition, particularly where there are psychosocial needs to be addressed.

A qualitative interview study with respiratory nurses in the Netherlands found that they concentrated mainly on smoking cessation advice in their clinics and that other self-management strategies such as providing exercise and nutritional advice or instilling confidence were less prevalent (Verbrugge et al., 2013). The authors recommended that inclusion of these forms of support and guidance, directed at individual patient's needs, would provide a more patient-centred form of consultation, which would lead to more effective self-management (Verbrugge et al., 2013). Parallels can be seen with the prescriptive model of primary care review consultations in this study and in the UK, where patients' psychosocial needs were found to remain unaddressed (Chew-Graham et al., 2013).

Disler et al. (2012) carried out a comprehensive review of the literature around self-management in COPD patients and highlighted several factors that influence individuals' ability to put this into practice. In addition to physical symptoms that may form barriers to self-management, the study drew attention to the psychosocial influences that can act on COPD patients. Psychological factors include the close interaction between the physical experience of breathlessness and the patient's psychological and emotional condition, illness perception, self-efficacy and optimism (Disler et al., 2012). Social influences that act upon people with COPD may include social isolation, loss of social role or financial support, culture and ethnicity (Disler et

al., 2012). Furthermore, perceived or actual stigma and self-blame associated with having a smoking-related disease may induce feelings of guilt and unworthiness leading to an unwillingness to take part in treatments to improve their condition (Halding et al., 2010). Although Disler et al. (2012) conducted a comprehensive review of the literature, they examined papers up to 2010 and it is possible that studies that are more recent may include accounts of strategies for identifying the psychosocial influences that form barriers to self-management in COPD. This chapter, therefore, aims to review the relevant literature from 2010 onwards.

Effing et al. (2012) reported on the findings of a workshop convened to examine the future direction for self-management in COPD. The workshop recommended that outcomes of self-management programmes should be assessed in terms of behaviour change and process variables, such as change in self-efficacy, attitude and social support, as well as the existing outcome measures of health status and hospital admissions (Effing et al., 2012). The paper also stressed the need to for consideration of the patient's perspective regarding the selection of topics to be included in a self-management programme, in order to increase motivation, and for healthcare professionals to be aware that the patient's needs may change during the course of the illness (Effing et al., 2012).

The following part of the literature review looks at the relationship between self-management and person-centred care. Recent literature around these topics will be explored and their relevance to the present study will be outlined.

2.1.9 Literature concerning person-centred care

Supporting patients with long-term conditions and encouraging them to take control of their illness can be an important part of patient-centred care. The World Health Organisation (WHO) defines long-term conditions as *"health problems that require ongoing management over a period of years or decades"* (WHO, 2005, p.13). During this time, patients with chronic illness will experience differing needs according to the stage of their illness, the presence of comorbidities, their social circumstances, psychological and emotional health and individual priorities and goals. It is therefore

important that the support and care they receive is coordinated across time and centred on their needs, values and preferences (WHO, 2005). This means that care needs to be tailored to the individual and requires a new way of thinking about service delivery and relationships, recognising that whole system approaches are needed to provide self-management support (Eaton et al., 2015). In other words, interactions designed to encourage self-management in people with long-term conditions should be person-centred and part of a joined-up system that meets the needs of the patient and their carers (Kurien, 2014). Relevant to this study is the idea that care planning for chronic illness should be person-centred and will incorporate the person's experience of day-to-day life over a period of time (Pulvirenti et al., 2011). Outcomes of patient-centred care, such as feeling understood, trust, or motivation to make changes in lifestyle can contribute strongly to both improved self-care and better adherence to health regimes (Epstein & Street, 2011).

The terms "person-centred care" and "patient-centred care" are often used interchangeably in the literature. The Royal College of General Practitioners (RCGP) in their report "An Inquiry into Patient-centred Care in the 21st Century" (2014) explains that person-centred care describes an individualised whole person approach to care. They continue by saying that, the term "patient" may suggest the traditional asymmetrical doctor-patient relationship, where the doctor imparts all the knowledge to the patient and tells them what is best for them, and that this is not in agreement with the person-centred view of care. However, they continue to use the term "patient-centred" in their report because "patient" is a term commonly used across the Health Service and is easily understood by professionals and the public. Nevertheless, they acknowledge that the philosophy of person-centred care forms the foundation for the patient-centred model of care "*We see considerable merits in the term 'person-centred' and would endorse its use to describe the vision of individual, whole person care*" (RCGP, 2014, p.10). The terms "person-centred" and "patient-centred" will both therefore be used in this review according to which is being used in the literature under discussion at the time.

Kitson et al. (2013) identified three core elements of patient-centred care: patient participation and involvement, the relationship between the patient and the

healthcare professional and the context where care is delivered. More recently, the Health Foundation (2014) described the four principles of person-centred care as shown below and stated that any health care experience should involve a combination of these principles (Fig. 2.2).

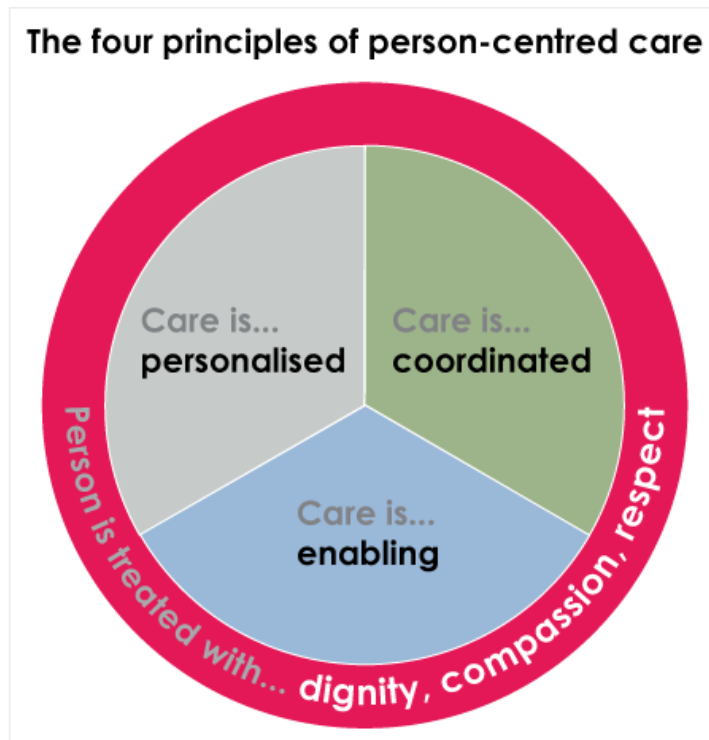


Fig. 2.2 The four principles of person-centred care (Health Foundation, 2014)

Powell et al. (2013) used qualitative data from COPD patients attending the European Respiratory Society's (ERS) Annual Congress, held in 2012, to gain a better understanding of their experience of care. The findings will be used to inform and educate healthcare professionals so they are able to provide more patient-centred care for people with COPD (Powell et al., 2013). Unmet needs expressed by the participants in this study included: psychological support, advice concerning physical activity and coaching for increasing motivation and they expressed an overall desire to be treated holistically, as a person rather than a disease (Powell et al., 2013). One of the recommendations that came out of the study was that treatment for COPD needs to address the patient as a whole, taking into account their comorbidities, and that COPD patients should be treated as individuals who want to be fully functioning

members of society (Powell et al., 2013). Participants also indicated that they experienced a lack of understanding about COPD from members of the public and also from some healthcare professionals, leading to feelings of stigma and discrimination. Education to bring about an increased awareness of COPD among those involved in the professional healthcare of people with the condition, and in the general public, would help to address these particular psychosocial needs (Powell et al., 2013).

Powell et al.'s (2013) paper is relevant to the present study in that it uses qualitative data to explore the experiences of people with COPD. However, the participants in the study were all attendees at the ERS Annual Congress and were people who were knowledgeable about their condition and engaged in their treatment. They were therefore not necessarily typical of COPD patients as a whole and this may have skewed the data.

Powell et al.'s (2013) study differs from the present study in that the views and experiences of healthcare professionals have not been recorded but a study in Finland looked at how nurses caring for older people perceived that they maintained a clear view of their patients' individuality (Suhonen et al., 2011). The questionnaire study found that, although the majority of the nurses perceived that they maintained the patients' individuality, there were several shortcomings in terms of patient-centred care in that they only moderately supported the patients' personal life situation and did not actively involve the families in the patients' care (Suhonen et al., 2011). The participants were nurses looking after older people in a hospital setting and may therefore have had less knowledge of, or contact with, their patients' relatives than healthcare professionals who are treating elderly people with long-term conditions in the community or in primary care.

Also of relevance to the current study is a qualitative study carried out by Cocksedge et al. (2011) who explored ongoing doctor-patient relationships in treating people with long-term and complex conditions. These relationships are referred to as "Holding relationships" and can produce benefits for both patients, GPs and the healthcare system. Patients value these relationships as reassuring and positive and GPs found them beneficial as a potential tool for changing health-related behaviour

as well as helping to avoid the need for secondary care in some cases (Cocksedge et al, 2011). GPs in the study recognized these holding relationships as part of their role and reported that they enabled them to provide holistic care for people with complex medical and psychosocial needs (Cocksedge et al., 2011). Developing an ongoing partnership between patient and clinician is also a theme found by Hudon et al. (2012) in their literature review of patient-centred care for people with chronic illness. Continuity of care, with a willingness from the clinician to respect patients' needs and preferences can empower the patient assist what the authors refer to as the healing process (Hudon et al., 2012).

Janssen et al. (2010) have proposed a patient-centred, palliative care programme for people with end-stage respiratory disease. They perceive that patients in this situation often experience psychosocial distress and have unmet care needs (Janssen et al., 2010). This is a situation that may be relevant to participants in the present study. It is a problem that needs to be addressed in the light of findings that suggest that patients with non-cancer respiratory disease, such as COPD, have far less support from palliative care services, in the last three months of their lives, when compared with cancer patients (Burt et al., 2010).

Thorarinsdottir and Kristjansson (2014) in their review of qualitative research findings, examined patients' perspectives regarding person-centred participation in healthcare. Their analysis of sixty studies found that human connection was fundamental to the patients and that the ideas of respect and equality were perceived as being of importance (Thorarinsdottir and Kristjansson, 2014). It will be of interest to discover whether these concepts emerge as themes from the data obtained from the participants in the COPD group of the present study.

Suhonen et al. (2010), in a quantitative questionnaire study, explored the perceptions of nurses towards individualized care for patients. They found that perceptions varied according to different care settings and that those caring for patients on a long-term basis in hospital had lower perceptions of individualized care than those working in psychiatric settings (Suhonen et al., 2014). Participants in this quantitative study were all nurses working in a hospital setting in Finland and the findings cannot therefore be directly compared with those of the present qualitative

study, which explores the perceptions of a number of healthcare professionals from different disciplines, with experience in primary, secondary and community settings. Recent literature has also discussed some of the barriers to patient-centred care. Healthcare professionals often report time constraints as a challenge. For example, nursing staff who were caring for older people, despite having expressed their support for the values of person-centredness, perceived that they were under pressure to complete everyday work tasks and that this was a priority (McCormack et al., 2010). Healthcare professionals are required by the system to objectify, quantify and code information supplied by the patient and this can be at odds with the patient's subjective account of their experience of illness (Lawn et al., 2011). However, some patients prefer healthcare workers to be the experts. They expect the medicalisation of their account and may be uncomfortable with shared decision-making (Lawn et al., 2011).

Another challenge arises when patients believe they need treatment that is actually unsuitable for their needs. For example, they may be requesting medication when information is sufficient and inappropriate prescribing of medication would be contrary to the principles of patient-centred care (Epstein & Street, 2011).

Fawcett and Rhynas (2014) talk about the possibility of conflict arising in nursing between ensuring that a patient is treated in a person-centred way and maintaining patient safety. By way of an example, they describe the difficulty of reconciling a patient's request for privacy whilst showering, with the need to ensure their safety (Fawcett & Rhynas, 2014).

Despite challenges such as those described above, a recent editorial in the BMJ calls for a change in the healthcare system towards patient-centred care in order to meet the needs of the rising number of people living with long-term conditions (Richards et al., 2015). The paper recognizes that collaborative working between healthcare workers from different disciplines, patients and carers and sharing decisions about care, services and research are challenging. However, Richards et al. (2015) suggest that person-centred care would make a significant contribution in meeting the challenges faced by the present healthcare system in the UK.

2.2 Summary of literature review

This chapter has reviewed examples of recent literature around topics relevant to the research question and aims of the present study. In this review, particular consideration has been paid to the causes of COPD and its symptoms, and how their perceptions of these affect the lived experience of people with this condition. Studies have examined other major influences on the day-to-day lives of people with long-term conditions, such as multimorbidity and especially psychological comorbidities, paying particular attention to how they interact with the experience of breathlessness in COPD.

Studies that have considered the psychosocial needs of this patient group and how these may remain unmet in routine review consultations, and those examining how far pulmonary rehabilitation contributes to the fulfilment of these needs, have been of relevance to this study. Finally, recent literature looking at the concepts of person/patient-centred care and how this relates to the support of self-management in people with long-term conditions has been reviewed.

This literature review has indicated that a qualitative study, carried out in the UK, which looks at both the lived experience of people with COPD and at the perceptions of healthcare professionals concerning the care they provide, would provide valuable information concerning how patients perceive their unmet psychosocial needs and how far the healthcare professionals feel that they are meeting these needs. The present study therefore aims to fulfil this requirement. In Chapter 2, the philosophical stance and methodology for this study will be outlined and this will be followed by a full description of the methods employed in order to carry out the research and analyse the findings.

CHAPTER 3 - METHODOLOGY AND METHOD

The literature review described in Chapter 2 informed and enabled the development of the research question for the study, which is as follows: The lived experience of people with chronic obstructive pulmonary disease (COPD): How are health providers meeting their psychosocial needs?

In the light of this question, this chapter outlines the methodological considerations and philosophies that underpin the study. It then describes the methods chosen and the procedure undertaken to carry out the study, ethics and data analysis.

3.1 Philosophical stance

This study is informed by phenomenological theory. Phenomenological research methods are based on individuals' descriptions of experiences of their everyday life, these descriptions are analysed in a systematic and methodical way and interpreted to uncover the implicit or explicit meanings contained therein (Giorgi, 1995). As such, phenomenological methods are designed for theory building, rather than theory testing. Phenomenological studies typically have the following features: an emphasis on a phenomenon to be explored, the exploration of this phenomenon with a group of people who all have experience of it, some form of philosophical discussion explaining the basic ideas involved in conducting a phenomenology, a procedure for data collection (often interviews), data analysis and a descriptive summary discussing the essence of the experience for the individuals involved (Cresswell, 2013). In summary, *"A phenomenological study describes the common meaning for several individuals of their lived experiences of a concept or a phenomenon"* (Cresswell, 2013, p76). This approach, therefore, is particularly suitable for the present study, which aims to explore the meaning for several individuals of their lived experience of having COPD, or of treating those who have COPD in a healthcare context.

Phenomenology is part of the interpretivist, or constructivist, tradition. Ontology refers to the study of the nature of reality and an interpretivist ontological view regards reality as something that is constructed and not 'set in stone'. A more

detailed discussion of interpretivism, and how it relates to this research, will continue below.

Firstly, in order to illustrate the philosophical background to this study, Saunders, Lewis and Thornhill's (2011) model, known as the "Research Onion" is used as a starting point for a more in-depth discussion of the philosophy underpinning this piece of research. Shown in Fig. 3.1, the research onion helps to explain the different philosophical stances held by researchers and how these inform the methods for the study and the type of analysis used.

Working from the outside of the "onion" towards the centre, this piece of research can be outlined as follows: it is being conducted from an interpretivist stance, using an inductive approach and a qualitative method. It employs a survey method and is a cross-sectional study. Data collection is carried out using semi-structured interview techniques and analysed using thematic network analysis.

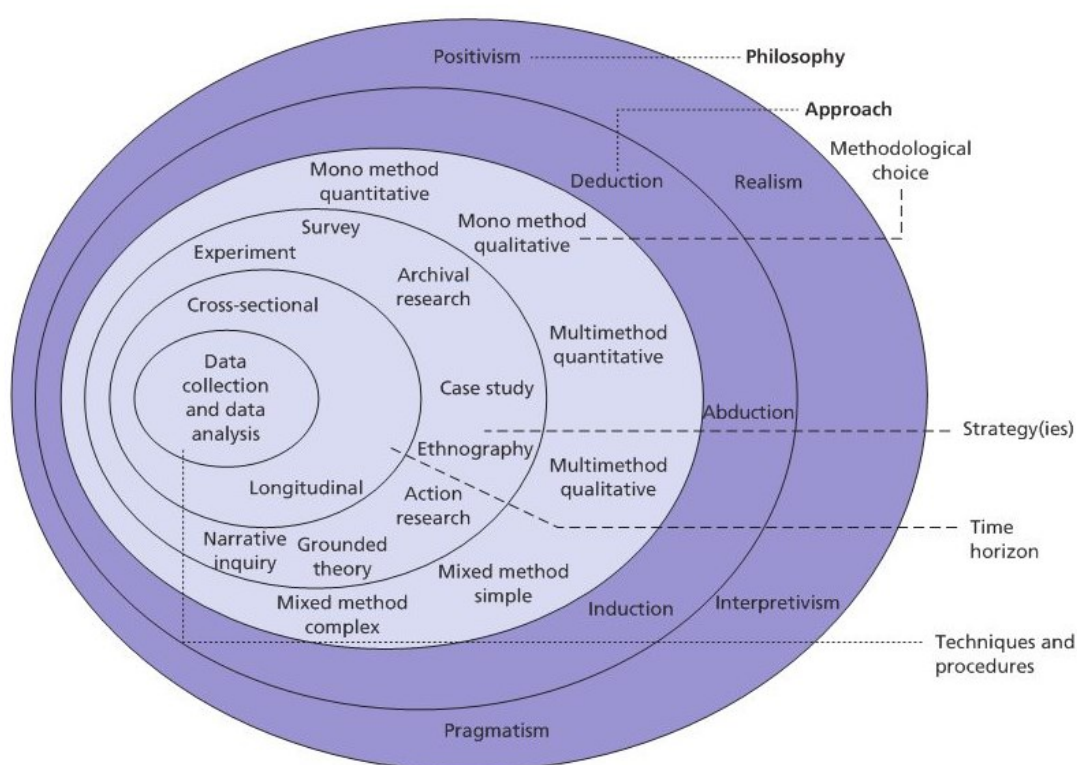


Figure 4.1 The research 'onion'
Source: © Mark Saunders, Philip Lewis and Adrian Thornhill 2011

Fig. 3.1 – The research onion from Saunders et al. (2011)

Ontology: The interpretivist approach is underpinned by a relativist ontology. This assumes that reality, as we know it, is constructed through meanings and understandings developed socially and is a theory-building approach. This is in contrast to the positivist or realist philosophies that are concerned with objective reality and underpin research methods involving theory testing. Interpretivism differentiates between the nature of phenomena that occur in the natural sciences and those studied by social scientists. Interpretivism argues that people, unlike non-human forms of life, put their own interpretation on their environment and lived experiences, and that these interpretations shape their actions. As a researcher with a background in psychology, my own approach to research reflects the interpretivist stance in that I believe that individuals' own interpretations of their lived experience are important factors in the way in which they behave. Consequently, an interpretivist paradigm requires responses to different questions than those within a positivist paradigm and therefore, a different type of data is required.

Epistemology: interpretivist researchers come from a subjectivist epistemology that is; they assume that the researcher and the object of investigation are linked and that researchers' values are inherent throughout the research process. In this study, my own background in psychology and experience of health research have strengthened the perception that reality is socially constructed and that my own values will contribute to this construction. I do not intend, therefore to put my own views and experience aside when collecting data for the study but to acknowledge their position in, and contribution to, the data.

This research is conducted using an inductive approach. An inductive approach is concerned with exploring the meanings of human attachments to events by collecting in-depth, qualitative data and is flexible in terms of structure in order to accommodate changes as the research progresses. Research who align with the interpretivist approach, frequently carry out their research using a qualitative methodology. Qualitative researchers believe that reality is socially constructed and the relationship between researcher and what is being studied is acknowledged as

an integral part of the research. They aim to explore how social experience is created and given meaning (Denzin & Lincoln, 2011).

The research method for this study is one that is commonly used by interpretivist researchers. The method used is that involving semi-structured interviews, conducted in a naturalistic setting, in order to explore the meanings that individuals ascribe to their experiences. The aim is to seek 'understanding' by focussing on subjective meanings (Broom and Willis, 2007). The method of analysis employed for this study is thematic network analysis. Thematic network analysis employs well-known, established techniques used in qualitative analysis and is a "*robust and highly sensitive tool for the systematization and presentation of qualitative analyses*" (Attride-Stirling, 2001 p.385). This method, when applied to rich data, such as that obtained from in-depth interviews with individuals talking about their lived experience of a long-term condition, is an established technique that provides a systematic way of breaking the text down into themes. The network presentation of the themes helps to explore the relationships between themes and to identify the unifying message of the data (the Global theme). The research method and method of analysis will be discussed in more detail later in this chapter but the following section of this chapter will describe the methodology employed for this study in more detail.

3.2 Methodology

A methodology is defined as the research design that determines our choice of methods and links them to the desired outcome (Crotty, 1998). The theoretical and philosophical stance of the researcher will determine the appropriate methodology for their piece of research. For example, objectivism is the position that regards social entities as existing in reality, external to, and independent of, social actors whereas subjectivism states that social phenomena are created through the perceptions and consequent actions of social actors (Saunders et al., 2012). These differing standpoints will influence the way the research is designed and the methods used.

A research study using quantitative methods is likely to be carried out by a researcher who adopts a positivist view. Positivism, adopts the stance of the natural scientist who prefers to collect data about an observable reality and searches for regularities and causal relationships in the data in order to create law-like generalizations (Gill & Johnson, 2010). Quantitative research methods look at the individual from an objectivist perspective. They emphasize the measurement and analysis of causal relationships between variables and quantitative researchers aim to carry out this work from within a value-free framework (Denzin & Lincoln, 2011).

In contrast, qualitative researchers stress that reality is socially constructed and acknowledge the relationship that exists between researcher and what is being studied. They emphasize the value-laden nature of inquiry and seek to find how social experience is created and given meaning (Denzin & Lincoln, 2011). Qualitative research is therefore particularly suitable for studies that aim to explore meaning in terms of how people experience events and how individuals make sense of their world (Willig, 2001). The present study, as one that aims to explore the lived experience of people who share a phenomenon (COPD) and the perceptions of those who care for them, will be carried out using qualitative methods.

The research design of this qualitative study is informed by phenomenological theory. The phenomenological approach was introduced by Edmund Husserl in the early twentieth century, in contrast to the positivist approach, which had underpinned the predominantly experimental research methods used in psychology at that time. As described earlier in the chapter, phenomenology rejects the concept of a concrete reality, but involves putting aside our existing understandings of objects or events and revisiting our immediate experience of them, in order that new meanings may emerge (Crotty, 1998). Phenomenological qualitative research seeks to establish psychological meanings, grounded in phenomena rather than in the quantitative, realistic or purely objective aspects of a situation. (Giorgi, 1995). Research which is influenced by phenomenology, therefore, focuses on the way individuals perceive events and how they talk about them. The phenomenological method is research based on descriptions of experiences in everyday life, which may be written by participants or the data may be obtained by interview and later

transcribed (Giorgi, 1995). In this study, a face-to-face interview method is chosen for data collection. The philosophical stance of the researcher, as described in the early part of this chapter, informs the choice of method for the study and the next section of this chapter will outline the choice of method for this particular piece of research.

3.3 Choice of method

This study involves the collection of data using semi-structured interview techniques. Individual interviews are useful when an in-depth exploration of the views or experiences of individuals are required (Petty et al., 2012). Methods of research using an interpretivist or constructivist paradigm include in-depth, semi-structured interviews conducted in a naturalistic setting i.e. in everyday life and the aim is to seek 'understanding', focussing on subjective meanings (Broom and Willis, 2007). Consequently, these in-depth interviews with individuals are often used in healthcare research where researchers and interviewees are able to co-create meaning by reconstructing perceptions of experiences and events related to health matters (DiCicco-Bloom & Crabtree, 2006). Furthermore, interviews are useful in enabling the exploration of issues that are too complex to be studied through quantitative methodologies (Burman, 1994).

Other methods considered for the study were, observation and questionnaires. Observational studies allow subjects to be observed over a specific length of time and their behaviours recorded, allowing for analysis of actual events rather than reported practice. However, time constraints would mean that it would only be possible to carry out observations over a short period. Furthermore, observational study does not give the opportunity to explore the meaning that individuals attribute to their experiences.

Questionnaires would give a wider sample of responses but, where closed questions are used, responses are restricted and open questions may give ambiguous responses. From the practical perspective, the cost of mailing questionnaires for a PhD study would be restrictive. More importantly in terms of the present study, a

questionnaire design would give less opportunity to explore the views of individuals in sufficient depth.

Semi-structured, one-to-one interviews, face to face, using non-directive, broad, open questions enable the researcher to obtain rich data in order to explore and understand the individual's lived experience. Semi-structured interviews are generally based around a small number of preset open-ended questions with further questions emerging from the evolving dialogue (Di Cicco-Bloom & Crabtree, 2006). Using a topic guide, rather than specific questions, enables flexibility and allows the researcher to follow up on unanticipated, but relevant, topics that the interviewee may introduce. It is important that the interviewer be prepared to depart from their planned itinerary in order to follow the interviewee's interest and knowledge (Di Cicco-Bloom & Crabtree, 2006).

Advantages of using semi-structured interviews for this particular study include the opportunity to carry out in depth discussion within a framework, to reveal similarities and differences between the views of COPD patients and healthcare workers in perceptions of care and to give clinicians an opportunity to reflect on their work in this area. In addition, interviews can be arranged to fit in with other activities and at a time and place to suit the researcher, patients and professionals and no financial burden is incurred.

Interviews can, however, pose challenges for the researcher. As in the case of questionnaires, closed questions can restrict the data. For example, in asking how a participant feels about the healthcare they receive for their COPD, a closed question such as "Are you happy with your GP practice?" may elicit a single word "Yes/no" answer. However, a question such as "How do you feel about the care you are offered for your COPD?" would potentially give more opportunity for an in-depth exploration of the participant's experiences. In addition, leading questions may skew responses to the preconceptions of the researcher. An example of this would be the question "How is your quality of life reduced now you have COPD?" which would be based on the researcher's assumption that having COPD is detrimental to the participant's lived experience. An alternative approach, in a question such as "What is your life like now?" would open up the discussion and give the opportunity for the

interviewee to talk about their own perception of the negative, and possibly positive, effects of having COPD. However, open questions such as the previous one, may lead the topic away from the one originally intended, in which case the prompts can be used to guide the conversation back to the original topic.

Another potential problem encountered in collecting face-to-face interview data is that the discussion may be limited if questions are set beforehand and this may mean that new information, which the interviewer did not anticipate, may be missed (Smith & Osborne, 2003). It is therefore important to use a topic guide, rather than set questions, to enable flexibility and the opportunity to incorporate unanticipated data, which may be an important part of the participant's lived experience. A further potential challenge is that using retrospective data in this way may be regarded as problematic, in that memory or deceit on the part of the participant may compromise the accuracy of the data. However, the interest of this study is in how the individual participant experienced a phenomenon and therefore these descriptions will be dependent on subjectivity and not on objective reports (Giorgi & Giorgi, 2007).

Taking into account the above potential challenges, the topic guide for the COPD participant group in the study therefore consisted of five, carefully chosen, open-ended questions with corresponding prompts to encourage further expansion on each topic, if required. The questions were designed to elicit data that would be relevant to the objectives of the study. Firstly, questions were introduced that would establish the extent to which the physical and emotional symptoms experienced by individuals with COPD affect their quality of life and ability to carry out their day-to-day activities. The opening question for each interview, "What is your life like now? Tell me about a day in your life." was designed to enable the interviewee to talk freely about their life in general and what was important to them. Prompts for this question included asking the participant about their family and social life. The second question, "How do you feel about your life now?" was then introduced in order to explore how the lived experience of the participant had changed since their diagnosis of COPD. Prompts were introduced with the intention of exploring changes in specific aspects of their day-to-day experience such as employment and to establish whether their illness had caused any impediments to their activities of daily living. Thirdly, the

question “Tell me about your COPD and how it affects you?” embraces all the physical and emotional aspects of the lived experience of the participant with relation to their COPD and how they cope with their symptoms on a daily basis. The next question, “How do you feel about the care you are offered for your COPD?” was important in exploring the perceptions of COPD patients regarding their care and treatment. In conjunction with the data from the HCP group interviews; this data will contribute to fulfilling the second study objective i.e. To understand how the experiences of clinicians in treating people with COPD are related to the perceived needs expressed by the patients. The final question on the topic guide for COPD patients is, “Is there anything else you want to tell me about living with COPD?”. This question will enable the participant to talk about any other aspects or issues of particular importance arising from their lived experience. This may be something completely new to the interview, an issue that not been introduced via the topic guide, or something that had been discussed earlier in the interview, which the participant wishes to expand upon.

The topic guide for the HCP interviews was subject to change according to both the particular healthcare discipline in which the HCP worked and the data previously collected from the COPD group. For example, primary care HCPs would be asked about the routine care of COPD patients whereas those involved with secondary care may wish to talk about treating patients in emergency care situations or those who have experienced acute admissions. Topics initiated by data from the COPD group and introduced into the HCP topic guide include difficulties patients experience in attending PR groups, follow-up after PR and treatments for emotional problems arising from living with COPD.

Kvale (1996) talks of the interview as a construction site for knowledge and emphasises that both the interviewer and interviewee therefore play their part in the construction of this knowledge. The use of a topic guide rather than prescriptive questions ensures that this construction of knowledge can take place within an interview that is conducted in a flexible manner whilst remaining aware of the aims and objectives of the study. The interviews with both COPD and HCP groups were therefore conducted with this in mind throughout the study.

3.4 Participants

In order to address the research question for this study, it was necessary to explore both the lived experiences of people with COPD and to understand how these experiences relate to the experiences of care as perceived by the healthcare professionals. Data were therefore obtained from two groups of participants: people with COPD and NHS healthcare professionals with experience of treating patients with COPD.

For the COPD patient group, the inclusion criteria were COPD patients aged 18 years and above who had sufficient understanding of the English language to enable the individual to take part in an interview conducted in English. Exclusion criteria for this group were: A diagnosis of lung disease other than COPD (e.g. asthma, lung cancer), serious physical illness or mental impairment such that the person is unable to understand or take part in a semi-structured interview or an insufficient understanding of English language, which will prevent the individual from taking part in an interview conducted in English.

For the healthcare professional group inclusion criteria were: Currently, or previously, employed by the NHS as either; General Practitioner, Practice Nurse, Psychological Therapist, Physiotherapist or other Healthcare worker, having experience of treating patients with COPD and having a sufficient understanding of English language to take part in a semi-structured interview conducted in English.

3.5 Recruitment

Purposive sampling was used in order to gain information and understanding of living with COPD and of treating patients with COPD. This type of sampling aims to ensure that the sample obtained can purposefully inform an understanding of the research problem and the phenomenon that is central to the study (i.e. COPD). The COPD patient group (n=9) comprised individuals with a diagnosis of COPD who were recruited from those attending a Pulmonary Rehabilitation (PR) group, a psychological therapy clinic for people with long-term conditions, a Breathe Easy

support group and a local GP practice. The group contained five male participants and four female participants. Their ages ranged from 57 years to 81 years, with a mean age of 69.7 years.

The healthcare professionals group (n=10) was made up of people currently, or previously, employed by the NHS, who were working with, or had previous experience of caring for, people with COPD. The healthcare participant group contained professionals with current or recent experience of working in primary care, the community, hospital inpatient wards, PR clinics and a hospital psychological therapies outpatient unit. All healthcare professionals and all but one COPD patients were recruited in the North-West of England. The process employed in the present study, as in most qualitative studies, whereby data collection and analysis are carried out concurrently eventually leads to a point where no new categories or themes emerge. This is defined as data saturation and, at this point, recruitment was completed and no new data collected (Di Cicco-Bloom & Crabtree, 2006).

Recruitment of patient participants took place as follows. The researcher contacted a local Breathe Easy support group in October 2012 and began attending monthly meetings at the invitation of the committee. Although the original purpose of these visits was to gain an insight into the purpose of the group and how it contributed to the care of people with COPD, it became apparent that members of the group were interested in the study and would be willing to take part in the interviews. Initially, informal contacts were made with members at these meetings and subsequently a short talk was given by the researcher, presenting the study to the members. Following the talk, information sheets were given out and individuals who expressed their interest in taking part, and met the inclusion criteria, were subsequently recruited to the study. The researcher continued to attend the Breathe Easy meetings until summer 2014 in order to ensure that participants felt she had a genuine interest in their views and their contributions had been valued. Of five members of the group who expressed an interest in taking part in the study, three were subsequently excluded because they had been diagnosed with a respiratory disease other than COPD. One of these people kindly offered to take part in a pilot interview after being

given a full explanation of what his contribution would involve. Two members of the Breathe Easy group were fully recruited to the study.

Recruitment from the PR group followed a similar method whereby the researcher contacted the group facilitator, who acted as gatekeeper, and was invited to attend one of the sessions. At a second visit to the PR group, the researcher gave a short presentation explaining the purpose of the study and what would be involved in taking part. Letters of introduction and information sheets were given out and interested individuals subsequently made contact with the researcher, through the gatekeeper, and were recruited if they met the inclusion criteria. One participant who contacted the researcher was recruited to the study from the PR group.

Further participants were recruited to the COPD group from those attending a psychological therapies clinic at the local hospital, which specialised in treating people with respiratory disease and comorbid anxiety. They were introduced to the study by one of the therapists, acting as gatekeeper, who gave out letters of introduction and information sheets to those who were interested in taking part. Those who subsequently contacted the researcher, and met the inclusion criteria, were asked if they would agree to take part in the study. Of the six people who expressed an interest in the study, two were subsequently too unwell to take part and a further two people declined. Two participants were recruited to the study from the psychological therapies group.

Having carried out interviews with participants from the Breathe Easy group and the PR group, it was necessary to continue recruitment until the point of data saturation was met. Further COPD patients were then recruited through a GP contact using the practice's Quality and Outcomes Framework register of patients with COPD. Patients were told of the study by the GP who gave those who expressed an interest, letters of introduction and information sheets. Those who wished to then contacted the researcher to receive further information. If the inclusion criteria were met, they were asked if they would agree to take part in the study. Four people contacted the researcher with a view to taking part in the study. One person was later too unwell to be interviewed and three participants were recruited to the study. One final

participant was recruited as a personal contact of a member of staff at MMU, who acted as gatekeeper.

Healthcare professionals were recruited through individual contacts with those working in the PR and psychological therapies teams in the local CCG area, local GP surgeries and the Faculty of Health, Psychology and Social Care at Manchester Metropolitan University (MMU). Of the fourteen healthcare professionals initially contacted by email, post or telephone, three did not respond, one declined due to work commitments and ten were recruited to the study.

Prior to recruitment, all individuals were given, or sent (by post or electronically), a letter of introduction to the patient or healthcare professional (Appendix 1 and Appendix 2), a copy of the study information sheet, for either COPD patient or healthcare professional (Appendix 3 and Appendix 4) and consent form (Appendix 5). The information sheet and consent form were developed in accordance with the British Psychological Society (BPS) Code of Human Research Ethics (2014) guidelines. Prospective participants were informed of their right to withdraw from the study at any point and were assured of their anonymity and confidentiality of their data. A period of at least two days was left between receipt of this information before a follow-up contact, by telephone or email, was made to arrange a time and day for the interview. Spare copies of the information sheet and consent form were brought to all interviews and each participant was given an opportunity to ask questions about the study before giving their signed, informed consent to take part in the study. A detailed description of the procedure for the collection of study data is contained in the following section of this chapter.

3.6 Procedure

The procedure for this study was designed in accordance with the aims of the study i.e. to explore the lived experience of people with COPD and to explore the views of healthcare professionals involved in the care and treatment of patients with COPD. Semi-structured interviews were conducted with two groups of participants: people

with COPD and healthcare professionals with experience of working with people who have COPD.

Interviews with participants in the COPD group commenced shortly after the first people were recruited to the study. Interviews were carried out in the homes of the COPD patients. This was primarily for the convenience of the interviewees, some of whom had difficulty leaving their homes due to their ill health or who needed to have their medication in close proximity. Conducting interviews in the participants' own homes also provided a more naturalistic environment conducive to the collection of qualitative data (Creswell, 2013). One exception was an interview with a member of the COPD group that was conducted over the telephone as the participant involved lived some distance away. Travel to their home would not have been feasible due to financial and time restrictions. No funding was available to reimburse travel expenses for either the patient group or healthcare professionals group. The interviews were arranged at a suitable time of day for the individual participants, taking into consideration the difficulties that some of them experienced in getting up and dressed in the morning and in preparing and eating meals. The researcher took time before the interview commenced to ensure that the participant was comfortable and that they were aware that they could stop the interview at any time if they felt unwell or needed a break. Throughout the interviews, openness and awareness of the participants' concerns were observed by using active listening and by reflecting and elaborating on the topics that were of greatest concern to the participants (Kvale, 1996).

Interviews with healthcare professionals were carried out at their places of work. Flexibility was important in terms of finding a suitable time and location for the healthcare professionals, for example, in their lunch break or before or after clinics and surgeries.

Interviews were semi-structured using topic guides consisting of five or six questions with prompts within each topic. Two topic guides were compiled before the interviews were conducted; one for COPD patients (Appendix 6) and one for healthcare professionals (Appendix 7) but these guides were subject to amendments the study progressed. In qualitative research, data analysis begins while data

collection is still ongoing, this means that an understanding begins to emerge which informs the questions that are being asked in the interviews (Di Cicco-Bloom & Crabtree, 2006). New topics were therefore added to both topic guides as new, relevant data emerged from the interviews. Data from the patient interviews subsequently informed the topic guide for the healthcare worker interviews, which took place at a later date.

All interviews were audio recorded using an Olympus WS-210S Digital Recorder, with the exception of the telephone interview where, due to a problem with the recording device, data were recorded in note form during the interview and from memory immediately after the interview had taken place. Audio recording is the most usual method of recording interviews for qualitative research studies (Kvale, 1996). It enables the interviewer to concentrate on the interview itself and provides a fuller recording than would be possible if notes only were taken (Smith, 1995).

Possible disadvantages of the audio recording of interviews include the suggestion that interviewees may feel uncomfortable about being recorded and that this may inhibit the interview process somewhat (Smith, 1995). Others have said that, because audio recording does not record any visual exchanges, it gives an incomplete record and the subsequent analysis is of the transcribed data and not of the interview itself (Bryman & Burgess, 1994). Field notes were recorded in a Microsoft Word document as soon as possible after each interview and these were referred back to during the analysis. The notes recorded the researcher's personal reflections about the interview and any non-verbal exchanges of relevance to the data. Reference to the field notes therefore provided additional data, which could be incorporated into the analysis. This enabled the researcher to analyse a more complete record of the interview, rather than verbal exchanges only and therefore overcome the issue raised by Bryman and Burgess (1994).

It is essential, when using recording equipment, to ensure that the researcher has the opportunity to practise with the equipment beforehand and to take replacement batteries and/or a replacement recorder to each interview to ensure good quality recording of the data (Di Cicco-Bloom & Crabtree, 2006). For the purposes of the present study, a practice interview was conducted with a fellow research student to

ensure that the researcher had full knowledge of how to operate the equipment to record the interview and to transfer the data to the computer, on which it was to be stored securely.

A pilot interview was conducted with an individual who did not meet the inclusion criteria for the study as, in addition to having been diagnosed with COPD, he also had another comorbid long-term condition, the symptoms of which overlapped with those of his COPD and may have confounded the data. The interview provided the researcher with valuable experience both in interview technique and in transcribing the data. Feedback from this individual helped to formulate the topic guide for subsequent interviews with people with COPD. For example, the participant in the pilot interview felt that it was important to ask future participants in the study how they first knew that they had a respiratory problem and how they felt when they were eventually diagnosed with COPD. This became an important issue in some of the subsequent interviews.

Interviews were transcribed verbatim by the researcher. Transcribing interview data is not without problems. For example, colloquial speech is often not made up of correctly constructed sentences and the transcriber may need to decide where to insert punctuation, which has the potential to alter the meaning of a sentence (Di Cicco-Bloom & Crabtree, 2006). In transcribing the data personally, with the support of the field notes recorded soon after the interview took place, the researcher in the present study aimed to avoid misinterpretation of the data.

3.7 Analysis

The data from each group of participants (the COPD group and the HCP group) were analysed separately. The data were analysed using thematic network analysis (TNA), following the steps designed by Attride-Stirling (2001). Initial coding of each set of data led to the extraction of a number of basic themes from the text. Categorisation of these basic themes led to the development of more abstract organising themes and from these the global theme for each data set was developed.

“The thematic networks technique is a robust and highly sensitive tool for the systematization and presentation of qualitative analyses” (Attride-Stirling, 2001, p.385). This method employs well-known, established techniques used in qualitative analysis. The method of analysis is very similar to that described by Braun and Clarke (2006) but differs in the presentation of themes in a network structure. Firstly, material is transcribed and transcriptions are coded through in depth engagement with the transcripts, reading and rereading these for meaning. From the codes, basic themes are extracted from the text; these are then categorized to summarize more abstract principles in the form of organising themes. The steps in the process of analysis is illustrated in Table 3.1 below. For this study, the data from the COPD group and that from the HCP group were analysed separately.

Table 3.1 Steps in analyses employing thematic networks – adapted from Attride-Stirling (2001)

<p>ANALYSIS STAGE A: REDUCTION OR BREAKDOWN OF TEXT</p> <p>Step 1: Code Material</p> <ul style="list-style-type: none"> a) Devise a coding framework b) Dissect text into segments using a coding framework <p>Step 2: Identify themes</p> <ul style="list-style-type: none"> a) Abstract themes from coded text segments b) Refine themes <p>Step 3: Construct thematic networks</p> <ul style="list-style-type: none"> a) Arrange themes b) Select Basic Themes c) Rearrange into Organising Themes d) Deduce Global Theme(s) e) Illustrate as thematic network(s) f) Verify and refine the network(s) <p>ANALYSIS STAGE B: EXPLORATION OF TEXT</p> <p>Step 4: Describe and Explore Thematic Networks</p> <ul style="list-style-type: none"> a) Describe the network b) Explore the network <p>Step 5: Summarise Thematic Networks</p> <p>ANALYSIS STAGE C: INTEGRATION OF EXPLORATION</p> <p>Step 6: Interpret Patterns</p>

In this study, the stages of analysis described above were conducted as follows: firstly, the transcribed text was read and reread to familiarise the researcher with the data and provide an initial coding framework in accordance with the guidance provided by Braun and Clark (2006). Once the coding framework had been decided upon, blocks of text were highlighted and allocated to different sections of the framework in order to ensure that every element of the participants' responses had been considered. Following this, initial themes were extracted from the coded text segments. However, these were very much subjected to change as further elements became apparent on rereading of the text. Themes were then refined as the data was further analysed.

The third step involved the construction of thematic networks by arranging and rearranging the initial abstracted themes in order to try to make sense of the overall message from each participant and to demonstrate the robustness of the themes which had emerged. This resulted in a number of basic themes. The basic, organising and global themes are presented in the next chapter with descriptions of the networks. Throughout the process, I returned to the original text to challenge and confirm the robustness of the final themes.

Table 3.2 Examples of the development of themes in Stage A of TNA for this study

Analysis step	Code/Theme	Participant Group	Example
1	Code	COPD	Daily living with COPD/coping
1	Code	HCP	Exercise
2	Theme	COPD	Loss
2	Theme	HCP	Personal experiences
3	Basic Theme	COPD	Childhood illness
3	Basic Theme	HCP	Barriers to care
3	Organising theme	COPD	Lifespan health
3	Organising theme	HCP	Patient care

Examples of organising themes for the COPD data for this study were lifespan health, loss and locus of control and organising themes for the HCP group included attitudes

and patient care. Following this, global themes are developed, illustrating the principal metaphors in the text as a whole. These themes and the relationships between them are then represented in web-like maps. The resulting thematic network can then be used as an organising principle and illustrative tool, which can facilitate interpretation of the text (Attride-Stirling, 2001). Returning to the original text, the final stages of the analysis are to describe and explore the network, summarise the thematic network and ultimately interpret the patterns (Attride-Stirling, 2001).

This method of analysis is an appropriate method to be used for the data obtained in the present study. It also provides the researcher with a systematic method of analysis, which gives a supportive guideline for those whose previous experience of qualitative analysis is not extensive. For these reasons, thematic network analysis was chosen as the method of data analysis for this study. Field notes were used to support the development of the final themes. Examples of these notes are shown in Table 3.3 (below).

Table 3.3 Examples of field notes

Bruce (COPD group participant)	Elsie (COPD group participant)
<ul style="list-style-type: none"> • Interview took place at 10.00 am at the participant's home, no one else was present • Participant had said in advance that he was not a typical COPD patient so my expectations were that he would be upbeat and not significantly affected by his illness • A large part of his narrative concerned his family and I used prompts to return to topics in the topic guide and in order to keep to the point • Followed his direction and used active listening throughout the interview • Participant's own sense of control came through in the way he discussed topics of his own interest • Interview took one and a half hours • Participant also talked about his work with Breathe Easy and as a patient representative on the local hospital board, which he finds very frustrating for several reasons. • Expressed some concern about the possibility of his name being associated with any apparent criticism of the hospital from which he receives care - I have assured him that I will remove the name of the hospital during transcription • After the recording has ceased, participant reported that he was pleased with the healthcare he received 	<ul style="list-style-type: none"> • Interview took place at 11.00 am at the participant's home, no one else was present • Did not phone beforehand as aware that COPD patients need time to get ready and did not want to disturb Elsie, she had forgotten I was coming, I offered to rearrange but she wished to continue • Has an idiosyncratic approach to life and appears to be resigned to living her life within certain limitations as a result of panic attacks • Appeared to be balancing COPD with her own preferences in that she kept cats despite having to take medication for allergy, thus demonstrating aspects of control over her environment and life • After the recording was completed, she demonstrated her own locus of control in telling me that she sought out and took part in online communities for people with COPD

3.8 Ethical issues

Ethical considerations were observed throughout the study. The study received ethical approval from the Manchester Metropolitan University, Faculty of Health, Psychology and Social Care Academics Ethics Committee and NHS National Research Ethics Service, North West, (reference 13/NW/0669). According to the British Psychological Society's (BPS) Code of Human Research Ethics (2014), the four ethical principles that need to be maintained in research are respect for the autonomy, privacy and dignity of individuals and communities, scientific integrity, social responsibility and maximising benefit and minimising harm. These underlying principles can be applied to the interview process in the following ways: reducing the risk of harm, protecting the interviewee's information, keeping interviewees informed about the nature of the study and reducing the risk of exploitation (Di Cicco-Bloom & Crabtree, 2006). These four principles were observed throughout the present study. Firstly, the researcher acknowledged that one group of participants who were COPD patients were vulnerable individuals due to their ill health and care was taken to ensure that they did not experience any physical or emotional distress whilst taking part. Care was taken before and during interviews to ensure that participants were comfortable and had access to medication if required. They were informed that they could stop to rest or withdraw completely from the interview at any time if they felt unwell or distressed.

To ensure that all participants, both in the COPD group and the HCP group, were kept informed of the nature of the study, verbal and written explanations of the purpose of the study and the anticipated extent of their involvement were given to them before they were asked to give their consent. The opportunity for the potential participants to ask questions or request further information was given and the researcher ensured that each individual had read and understood the information sheet (Appendix 3 and Appendix 4) before they signed the consent form (Appendix 5). The participants were informed of their right to withdraw from the study at any point and details concerning anonymity and confidentiality were explained to them.

In order to protect the participants' information and avoid exploitation, in both the COPD group and the HCP group, each individual was assigned a pseudonym and any

person identifiable data was removed from the interview data during transcription. Electronic recordings of interviews, anonymised transcribed data and field notes were stored on a password-protected computer and hard copies of consent forms were kept in locked filing cabinets in a secure research office, accessed only by card key, at MMU.

Throughout data collection and analysis, credibility, dependability, confirmability and transferability were emphasised (Lincoln and Guba, 1985). Credibility is concerned with the believability of the results of the study and is ensured by using rich, in-depth data such as that obtained from semi-structured interviews. In qualitative research, the number of participants is not as important as the richness of the data (Lincoln & Guba, 1985). Dependability ensures that the findings from the research are consistent and could be repeated by an independent researcher. In order to ensure dependability, the original researcher must report each process in the study in detail and to a standard such that others would be able to understand and repeat the methods employed (Lincoln & Guba, 1985). Confirmability looks at how the research findings are supported by the data. In order to establish confirmability of the conclusions of the study, the researcher must demonstrate how each decision was made throughout the analysis process (Lincoln & Guba, 1985). Finally, transferability is concerned with showing that the findings of the study can be applied in other contexts. In order that the reader is able to compare the details of the research to their own situation, the original researcher must provide a detailed account of the situation and methods employed in the study (Lincoln & Guba, 1985).

Summary

This chapter has outlined the philosophical background to methodological decision making and the method adopted for this study. Interviews were carried out with patients with COPD and with health care professionals involved in the care of such patients. The next two chapter/s report on the findings from these two groups of participants.

CHAPTER 4 – RESULTS FOR COPD PATIENTS

As noted in chapter 3, the data from each group of participants (the COPD group and the HCP group) were analysed separately. The data were analysed using thematic network analysis, following the steps designed by Attride-Stirling (2001). Initial coding of each set of data led to the extraction of a number of basic themes from the text. Categorisation of these basic themes led to the development of more abstract organising themes and from these the global theme for each data set was developed.

This chapter outlines the results from the COPD patient participants. It summarises demographic data then gives a diagrammatic representation of the thematic network (Figure 4.1). The chapter then discusses the data from this group of participants in detail, exploring and summarising the thematic networks and interpreting the patterns contained within them.

4.1 Participants' demographic data (COPD group)

Nine patients acted as participants in this research. They are identified by the following pseudonyms: Alison, Bruce, Clive, David, Elsie, Florence, George, Harriet and Ian.

Table 4.1 demographic information about patient participants

Participant	Age range (years)	Sex (Male/Female)	Time living with COPD (years)	Employed/ Retired
Alison	65-69	F	>20	R
Bruce	70-74	M	6-10	R
Clive	65-69	M	0-5	R
David	55-59	M	6-10	E
Elsie	65-69	F	0-5	R
Florence	75-79	F	>20	R
George	75-79	M	>20	R
Harriet	80-84	F	6-10	R
Ian	60-64	M	0-5	E

4.2 Results for the COPD group

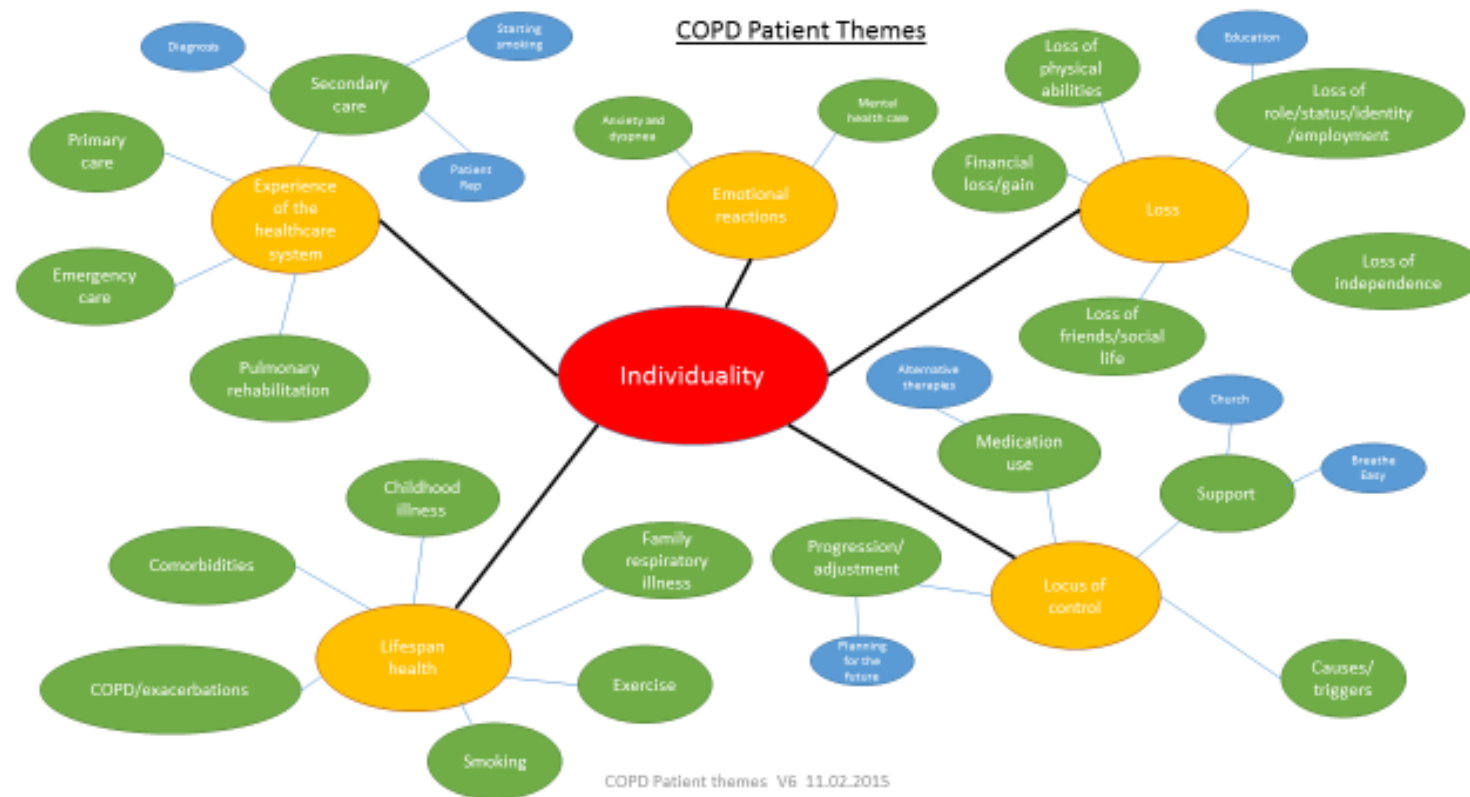


Fig. 4.1 Thematic network illustration for the data from the COPD group

Five organising themes were identified from the data taken from the COPD group. The first of these was “Lifespan health” which had the following basic themes associated with it: childhood illness, family respiratory illness, exercise, smoking, COPD/exacerbations and comorbidities. The second organising theme was “Experience of the healthcare system”, which had the following basic themes associated with it: primary care, secondary care, pulmonary rehabilitation and emergency care. The theme of secondary care also had three outlying themes related to it, which were diagnosis, starting smoking and patient representative. These were topics that the data suggested were particularly important to three different individual participants in the COPD group. Another of the organising themes was “Emotional reactions” and the two basic themes related to this were anxiety and dyspnoea and mental health care. The theme of “Loss” had five related basic themes, these being: loss of physical abilities, loss of role/status/identity/employment, which had an outlying theme of importance to one of the participants (education), loss of independence, loss of friends/social life and financial loss/gain. The final organising theme was “Locus of control” and its associated basic themes were medication use, with an outlying theme of alternative therapies, support, with outlying themes of church and Breathe Easy, causes/triggers and progression/adjustment, with an outlying theme of planning for the future. The global theme of “Individuality” will be discussed later in the chapter. These themes are summarised in Table 4.2 (below).

Table 4.2 – Themes from the COPD participant group data

Global theme	Organising themes	Basic themes	Outlying themes
	Lifespan health	Childhood illness	
		Family respiratory illness	
		Exercise	
		Smoking	
		COPD/exacerbations	
		Comorbidities	
	Experience of the	Primary care	
		Secondary care	Diagnosis
			Start smoking
			Patient rep

Individuality	healthcare system	Pulmonary rehabilitation	
		Emergency care	
	Emotional reactions	Anxiety and dyspnoea	
		Mental health care	
	Loss	Loss of physical abilities	
		Loss of role/status/identity/employment	Education
		Loss of independence	
		Loss of friends/social life	
		Financial loss/gain	
	Locus of control	Medication use	Alternative therapies
		Support	Church
			Breathe Easy
		Causes/triggers	
		Progression/adjustment	Planning for the future

4.2.1 Lifespan health

Narratives about lifespan health constituted a large part of the patient interviews. This was related predominantly, directly to COPD but people also discussed other childhood and family respiratory illnesses, exercise and its part in pulmonary rehabilitation (PR), their smoking history, their attitudes towards smoking and its contribution to their present state of health, experiences of exacerbations of COPD and their experience of co morbid health conditions.

4.2.1.1 Childhood illness

Four of the people interviewed referred back to their experiences of childhood illnesses and all of them said that they felt these had contributed in some way to their development of COPD. These narratives were sometimes detailed and vivid and, despite the accounts of events that took place in their early childhood being largely based on information given to them by close family members, the participants considered them relevant to their present day experience.

Alison spoke about how she had had problems with her chest since she was a couple of weeks old. She recounted, *"I was born with a bad chest"* (22) and *"...bronchial pneumonia when I was two weeks old...my mum said I used to cough till I was nearly purple"* (118). She talked at length about her recurrent respiratory problems and of how lack of adequate healthcare meant that she missed large amounts of time at school. She recalled, *"...but in those days you didn't get a doctor, so I think it was ignored a lot, you know, so. Besides goose grease on your chest"* (124) and *"No antibiotics I don't think it's just, I don't think I ever went to the doctor's much with those. Fifteen, I think, was the first time I started going to the doctor's"* (129). There was no indication that Alison felt that the lack of medical attention was due to neglect, it was stated as a fact that, in her early childhood, primary healthcare was not readily accessible. However, having been born in 1949, she would have been eligible to receive healthcare under the NHS, albeit at the very early stages of availability of antibiotics on prescription. Although she recounted their childhood experiences without displaying any emotion, there was an inherent sadness in her narrative, particularly when she spoke about how her mother said that it *"wasn't worth the paper and the pencil"* (590) for her to take the 11 plus because she had missed so much schooling due to her respiratory illnesses.

Two interviewees had been diagnosed with whooping cough as young children. Elsie was hospitalized as a child and indicated that it had been suggested to her that her bronchiectasis, which she had been diagnosed with prior to their diagnosis of COPD, could have been a result of the damage inflicted by the whooping cough. This was an example of how some patients' views about the development of their condition are initiated, or reinforced, by healthcare professionals and can be used to divert blame from the patient's own lifestyle choices (in the case of COPD, this would generally be in respect of cigarette smoking). They explained, *"I mean the bronchiectasis they reckon was erm, I had whooping cough very, very badly when I was a child...I was hospitalized with it"* (438). George recounted how his mother had told him some years ago that he was *"very bad"* (36) with the same illness at six months' old and, although he did not verbalise this, their facial expression and tone of voice reflected the serious nature of her comment. He added that, *"maybe the weakness was set in*

then” (38). Recurrent bouts of pneumonia were recalled by Florence who also felt that this childhood illness was the start of her respiratory problems later in life, “I had pneumonia every year till I was four...I think that set it all off” (250).

These accounts of childhood respiratory illness serve as a reminder of how healthcare in the UK, with respect to respiratory disease, has progressed during the lifespan of the study participants. The majority of them will have experienced medical care before and after the start of the NHS, the introduction of antibiotics, widespread immunisation programmes against whooping cough and, more recently, the introduction of the Quality and Outcomes Framework (QOF) (Department of Health, 2003) into general practice, which has led to changes in the way chronic diseases are managed in primary care.

4.2.1.2 Family respiratory illness

In addition to talking about their own childhood experiences of respiratory illness, several of the interviewees described how other members of their family had suffered from similar problems. Some believed that their family history might have had some influence on their development of their COPD.

No clear overall picture concerning family respiratory ill health emerged from the data. Some felt there could be a hereditary link; one appeared to imply that infection in a close family member could have affected the functioning of their own respiratory system and others spoke about there being a number of members of the family with similar problems without offering any possible explanation or connection regarding their own ill health.

Elsie thought that her mother’s diagnosis of TB when Elsie was a young child might have been connected to the development of her own respiratory problems in later life although she did not elaborate on how this would have come about. She simply stated, *“...my mother, when I was five, had TB...so there’s a possibility, according to the, you know that it could...all stem back to that” (443).*

Alison and George both talked about having several close relatives with similar respiratory problems. Alison described a strong family history of respiratory disease when she said, *"...all my family's got, or had, (respiratory illness) my brother's just been diagnosed with emphysema...my dad had emphysema...my grandma...I think she either had bronchiectasis, with all that mucus that she did cough up, or she had this (emphysema)...and my mother had emphysema as well"* (154). Alison was the only person in the COPD group who said that they had been tested for the hereditary form of COPD. This is a rare genetic tendency to develop COPD called alpha-1-antitrypsin deficiency, which causes COPD in a small number of people (about 1%). This occurs because alpha-1-antitrypsin is a protein that protects your lungs and, in individuals where this protein is deficient, other enzymes occurring naturally in the body can damage the lungs (British Lung Foundation (BLF), 2015). This causes people to develop COPD at a younger age than usual, often under thirty-five. Alison was diagnosed with emphysema at the age of forty-eight but her test for alpha-1-antitrypsin deficiency was found to be negative.

However, in the case of George, they felt that his grandparents' illness could be due to their employment history rather than some form of familial tendency to chest problems. He said, *"...my grandmother...she had the same thing...they didn't call it COPD I don't think, but she was in a cotton mill for forty-odd years...my grandfather...he was an overlooker, I think in the same cotton mill...he got the same thing"* (452).

These individuals therefore saw childhood respiratory illness, family respiratory conditions or occupational conditions as possible contributory factors in the development of COPD later in life. Bailey et al. (2009) explored the stories of people with COPD and found a wide variation in their causal explanations for their illness, several of their participants believing that the cause of their illness was more complex than simply having been a cigarette smoker. They concluded that, in order to provide individualised care for their patient, it was important for clinicians to consider these alternative understandings instead of concentrating only on the 'facts' relating COPD to cigarette smoking, (Bailey et al., 2009).

4.2.1.3 Exercise

Attitudes to and experiences of, exercise covered a broad spectrum of views within this sample of COPD patients. The participants' experiences of exercise were similar in the way that they all described a reduction in their physical abilities (see also "Loss" theme) however, individual differences were apparent in that several of them acknowledged the importance of exercise and had adapted their regimes in order to be able to continue with some form of exercise. This may be as a result of information gained from a course of PR or from their own research and awareness regarding a healthy lifestyle. In contrast, it appeared that some had very little acknowledgment of the contributions that exercise could bring to their well-being, others were aware of this but found it difficult to maintain a regime of exercise.

Some interviewees gave an impression that they were resigned to the fact that they were not even able to walk as far as they once could, or carry out routine tasks such as climbing the stairs. Clive for example, said, *"I've never been up that road walking since"* (49) and *"I've got to stop at the top of the stairs and take a rest for three or four minutes"* (243). David also stated, *"I can't go out and walk around as much...I have a walking stick now"* (81). Clive and David had both been active people but appeared now to accept that this reduction in physical ability was an inevitable part of the progression of the disease.

Florence talked about avoiding situations where she was likely to become breathless, *"I get out of breath going up any stairs...in fact, I try to avoid them really, you know, if I can...and get a lift"* (222). Similarly, Harriet saw her breathlessness as a sign that she should stop whatever physical activity she was engaged in at the time. This appeared to be a common misconception amongst COPD patients who have not experienced education about the need for exercise and are not aware of the benefits that can come from a personal exercise plan, such as those taught as part of a PR programme. Harriet described how she interpreted her breathlessness as a sign to stop exercising, *"I do get breathless...when I do, I stop...it tells me, you know, don't do it any more...I suppose that's a good sign"* (78). She also explained how they used the car for short journeys, *"...because I've got a car outside, you get lazy...I could walk to the shops...but I do get in the car"* (263).

Harriet therefore regarded breathlessness as a sign that she should stop the activity she was involved in at the time and felt that this was a good thing. These avoidance measures, taken by some COPD patients, are contrary to the advice of healthcare professionals who work in PR and who emphasise the need to take part in individually designed exercise regimes in order to avoid becoming deconditioned. It is interesting to note that these four people in the COPD group had not completed a course of PR. Clive did not complete their PR course as he felt he was not getting any benefit from it at that stage of their illness. However, in hindsight, he felt that he might have been mistaken in not completing the course. He remembered, *"But that was in the early stages...and I must admit I was a bit erm, what can I say, complacent. Because at the time I didn't feel as bad as what I do now...and the exercises what they ask you to do were just that easy at the time... and I ended up not going"* (211).

David and Florence however did not show an awareness of the existence of a PR course and Harriet said that she had not been asked to go on one and would not go if she were asked. Arnold et al. (2006) found that more people could be encouraged to participate in PR if the referring doctor had a positive approach. Furthermore, adherence to a course of PR could be improved with appropriate social support for those living alone (Arnold et al., 2006). It is therefore possible that, had these individuals been referred to a course of PR by a healthcare professional who expressed the opinion that it would be beneficial for them, they may have felt encouraged to take part and, with appropriate support where required, subsequently would have benefitted from the experience.

Others were aware of the need to exercise and had continued to do so in ways they felt comfortable with. Two people in particular made exercise an important part of their daily routine. Bruce initially took part in an exercise scheme, which followed on from his attendance at a PR course and found it beneficial. He then continued to exercise by going to the gym and following his own regime, *"I also go to the gym twice a week and...have my own schedule which I have invented for myself because you can't do too much cardio"* (366). Bruce also finds that he can no longer run, but, despite being told that he has severe COPD, he still exercises by walking in a way that he enjoys. He explained, *"...nowadays you see I can't run any distance at all"* (280)

but *"I don't mind walking on my own as long as you can walk a long way and find different things of interest"* (353).

In addition, George played crown green bowls and regularly used his own gym equipment at home and, having been diagnosed with COPD almost thirty years previously, felt that it had helped him to stay relatively well over a long period of time. He spoke about the benefits of their exercise regime, *"I enjoy (crown green) bowls and it's good for me...I try and get a bit of exercise...treadmill"* (11), *"...there's the steps"* (21) and *"I'm seventy-seven now...forty-eight when I was diagnosed with this...so I've done all right"* (131).

The social aspect of exercising in a group was important to at least one of the interviewees who was content to enjoy still being a part of the group when she could no longer take part in the exercises. When they did feel unable to continue with the physical activities, Alison continued to attend the PR classes because of the benefit she experienced from the social contacts she made there. She recalled, *"I used to go on the rower...the bike and the walking the...treadmill...but there again, I went to the social because I couldn't do either in the end...but it was good"* (248). Interestingly, this individual is also a member of Breathe Easy who values the support of friends and now finds that she spends more time with those who have a similar medical condition. She commented, *"...my friends now, is the same situation...like the lung, we've all got the same thing...so if we all go out for a day...we know how far and how limited we can, you know, what we can do"* (48).

4.2.1.4 Smoking

Of the nine COPD patient interviewees, seven talked about their smoking history, one, Ian, referred to himself as an atypical COPD patient in that he had never smoked and Harriet did not include any reference to smoking in her interview. Some reported starting to smoke in their teenage years. For example, Clive said that he had smoked *"...from being about fourteen...or fifteen"* (106) and Elsie remembered, *"I was about sixteen or seventeen...when I had my first cigarette"* (468). There was reference made to the concept of smoking as being regarded as a harmless pastime at that time. Elsie

recalled, *"When I started smoking back in the sixties, nobody thought it was wrong"* (460) and Florence simply commented, *"It was the in thing then wasn't it?"* (319).

An interesting account was given by Florence who told how she started to smoke when she had just given birth to her daughter and was encouraged by other patients to join them as they were smoking in the hospital toilets. Although she recounted this as an amusing anecdote, it provided a good insight into society's attitude to smoking at the time when most of the people in the study were starting to smoke. It also indicates the strength of peer pressure on Florence and how, although she had never felt tempted to smoke in her teenage years, she felt the need to be accepted by the group of new mothers among which she found herself. *"I never smoked as a teenager...I never had the money anyway"* (345), *"I never smoked till after I had my daughter...I was in hospital...they had you in for ten days at that time and the other women were going to the toilets for a smoke 'Are you coming?', I says 'I don't smoke,' 'Oh, come on and have a cigarette'...and I can always remember my husband coming to see me and I said 'Will you buy me ten fags?' he says 'What for?'...and I told him...and he bought me ten fags"* (287).

In later years, when it became apparent that smoking was dangerous to health, some of the COPD group continued to smoke because either they found it too difficult to stop, or because they thought they might remain unaffected by adverse effects. However, both of these interviewees expressed regret that they had not stopped sooner than they did. Clive said *"I still carried on smoking...which I shouldn't have done, which I mean that's all right seeing it in hindsight now"* (100) and similarly, Elsie regretted continuing with the habit, *"I wish I hadn't got it but I was obviously one of those who, I carried on smoking thinking 'Oh, it won't happen to me'"* (391).

Smoking cessation was also very much an individual matter; some had tried to give up with help on previous occasions but then reached a point where they felt able to do it themselves. Two people said that they had been given help with smoking cessation, in the form of tablets or patches, in the past but that it had been unsuccessful and there came a point where they felt they had to do it for themselves. David and Elsie talked of how, despite the addictive nature of cigarettes, her deteriorating health meant that she had to stop. David explained, *"...well, I've had*

patches in the past well before now and those cigarette things and...but this time I just decided to" (150). Elsie went into more detail about her smoking cessation and referred to it as using mind control, *"I'd tried Champix, a couple of years previously. I'd had patches and they'd made my blood pressure soar so high that I had to stop them. (Coughs) and I knew that the only way to give up would be, mind control if you like"* (127) and *"I gave up smoking with no help whatsoever...erm, I got up one day, I felt really rough. The weather was horrible, I'd got no cigarettes and I couldn't be bothered to get dressed, get in the car and go and get some. And that is how I gave up smoking"* (123).

Interestingly, Bruce and Elsie both spoke at length about how unwell they felt during the first few weeks after they had given up cigarettes and they were surprised to find that their doctors agreeing that this was not unusual. Bruce, in particular, found this distressing to the extent that he contemplated starting to smoke again. He recalled, *"Anyway, when I stopped smoking instantly, and that's when I suspected I'd got COPD, everything was worse, everything was worse and you think 'Oh, I almost feel like starting again'"* (186). He continued, *"I've asked three doctors since then...and I said 'Has anyone who has stopped smoking ever said that they feel terrible...they feel awful?' and all three of them said 'Yeah, most people who stop smoking are like that'"* (200). Elsie had a similar experience, *"I put it down to the stopping smoking...erm, getting rid of all the muck. And that's what the doctor kept saying...'well, you know it's got a lot of years of smoking to get rid of'"* (109).

Although all the interviewees with smoking history talked about having quit smoking, the global theme of individuality was still evident in that, despite being aware of the dangers, each one made an individual decision to stop smoking at a time, and with a method, that was right for them. It is of interest to note that, in terms of the research question for this study, none of the interviewees spoke positively about receiving help with smoking cessation from healthcare professionals. Although they spoke of previous attempts at smoking cessation with the assistance of medication, they did not report any success in this respect and therefore gave no indication that this particular psychosocial need was being adequately addressed.

4.2.1.5 COPD exacerbations

Once again, despite the commonality of the condition amongst the interviewees, there was considerable variation in how they experienced the symptoms, particularly in terms of the number and severity of exacerbations and/or chest infections. Although, as would be expected, those with more severe COPD tended to experience more respiratory problems of this kind, this was not always the case.

For example, although Bruce had been diagnosed with severe COPD, he had experienced only two exacerbations of his illness and had never required in patient care for their COPD. He said, *"I've just entered the severe COPD"* (301) but *"Then like the GOLD grade...is C, and that means you have a very high risk of exacerbations, in my whole time I've only had two exacerbations and you just think basically it's bronchitis"* (319). Harriet also said that she had only experienced one episode of acute respiratory illness but that it had necessitated a weeks' stay in hospital for the treatment of pneumonia.

Some of the people in the study had experienced serious acute health problems. Clive and David, in particular had experienced sudden deteriorations in their health on several occasions. Expressions such as *"I could hardly breathe"* (Clive, 180), *"struggling all night"* (David, 121) and *"fighting for my life"* (David, 124) were used and, indeed, on occasions, emergency service personnel had validated these fears.

For example, Clive gave accounts of two of his exacerbations, *"I could hardly breathe and I came downstairs and I went on that (nebulizer) and I took two, and lay down on there with a cover over me and went to sleep...I ended up taking twenty-four of them....in one night. And then when my wife got up...and saw the state I was in down here, she phoned an ambulance straight away and they took me in"* (180) and *"...there was another time when I had an attack...I fell over in the kitchen, well I fell three times in the day...they sent me a doctor out who admitted me straight away into hospital"* (275). Similarly, David recalled, in graphic detail, one incident where he had been taken acutely ill and the seriousness of the situation had prompted the paramedic to suggest that he had done the right thing in calling the emergency services. He recalled, *"I had pneumonia...I'd been struggling all night breathing...and*

then in the morning... I couldn't put two words in a sentence...and it was like fighting for my life. (partner) phoned for an ambulance and he said 'Well I'm glad you phoned' he said 'another fifteen minutes and you would have been calling for an undertaker not me'" (119).

Prompt medical attention was of great importance to the COPD patients in these acute situations and, as in the above examples, there was a sense of safety and security brought about by their admission to hospital or treatment by a medical professional. Alison also expressed this sense of relief at being in expert hands, *"I had a bad chest infection and my lips were blue and they said 'You need oxygen' and they got it there and then for me"* (378).

The cases where individuals received prompt medical attention were good examples of how they felt that the healthcare system was meeting their psychosocial needs in terms of allaying their fears and taking them to a place of safety and expertise. In fact, although their needs may have been met at that time, one of the participants indicated that hospital admission was not always medically necessary. David reported that, during the previous year, *"I think I phoned for an ambulance about sixteen times and out of that I think there was ten or eleven actual admissions...the other times I've been in between five to seven hours...and they just kicked me out...cos I've got all the equipment here I need"* (170).

Others talked about the frequency of their bouts of illness. Florence said, *"I do get chest infections quite, er, regularly...in the winter"* (142) and *"I get them more than I think other people get them"* (468) and George spoke of having experienced four chest infections in recent years. Elsie was the only person in the COPD group who attributed the effectiveness of their routine medication to the avoidance of exacerbations, *"...before I went on the regime I'm on now...I used to have flare-ups, the exacerbations"* (550).

4.2.1.6 Comorbidities

The global theme of individuality was also apparent in the interviewees' different experiences of comorbidity. Comorbidities were frequently discussed in the interviews. Some of these conditions had different origins from COPD but were important in that they acted alongside the COPD to affect the day-to-day lived experience of the individuals.

For Elsie, the combination of COPD and panic attacks, which she had experienced for many years before her diagnosis of COPD, made it impossible for her to go out alone. She said, *"I don't do much because, but that's nothing to do with the COPD, erm, I suffer panic attacks...I don't go out on my own"* (6).

During Florence's interview, she talked about having breast cancer, which had been diagnosed four years previously, and it was apparent that this diagnosis and treatment had become her primary health concern, over and above their COPD. She reported that she was in remission at the time of the interview but it was apparent that the cancer diagnosis still affected her lived experience. In particular, she talked about how much she used to enjoy travelling but said *"In fact I've not been abroad for is it three or four years erm, because I'm a bit frightened in case anything, you know if...it's not my chest...it's the cancer in case anything...crops up, you know"* (88). In addition, Florence had back pain, which affected her mobility, *"I can't walk like I used to...but that isn't (COPD) it's mainly my back"* (26).

Harriet and her husband both had cardiac pacemakers, which she referred to as being necessary to *"keep going"* (483).

David, in particular, had several comorbidities, both physical and emotional, all of which interacted to cause significant detriment to his quality of life and, ultimately, to his life expectancy. He explained, *"Yeah, I've got: severe COPD, chronic bronchitis, underactive thyroid, high blood pressure erm, angina, er excessive fluid, anxiety and depression and...I have a tablet for my heart as well because of the pressure what my lung's putting on that"* (220) and *"He (the consultant) said and it's the fluid which is going to cause the problems, the excess fluid"* (251).

For others, it was difficult to establish the relationship between symptoms caused by COPD, various comorbidities and possible effects of medication, but the resulting experience proved, for some, to be confusing and to have a detrimental effect on their quality of life. For example, Alison talked about having symptoms that were unrelated to her respiratory problems but may, in fact, have been caused by some of the medication she had to take for her COPD. She said, *"...like losing weight and my stomach and having tests for stomach. Well, they thought it was cancer at the time, but it's that erm, er GERD, you know, the gastric reflux"* (469).

4.2.2 Loss

Loss is a theme that was present in all the interviews carried out with participants in the COPD group. However, for some individuals it was considered from a practical point of view, in terms of a loss of physical ability whereas others spoke of the emotional component of loss brought about because of experiencing the symptoms of COPD.

4.2.2.1 Loss of physical abilities

Some degree of loss of functional capacity was evident in every interview in the COPD group and several referred to their response to this in terms of "slowing down". For some, it was the effect this had on their ability to self-care and being able to provide themselves with sufficient nutritional input that came across as most important.

Participants talked about the difficulties they faced when trying to carry out their personal care and other activities of daily living. These participants reported in some detail how they felt when they had completed a task that had taken them much longer than it used to before they became unwell. Harriet used the term "slowing down" several times during her interview and spoke about how this affected her activities of daily living. She said, *"Since I was diagnosed in 08 for the emphysema...I've slowed down a lot since then."* (49) and *"It takes me much longer just to prepare cereal and toast"* (88). Similarly, Clive explained the difficulties he

experienced getting up and about each morning, *"It'll take me an hour to get downstairs"* (11) and *"By the time I've got up, had a swill, been to the toilet and got back, I'll sit on my bed for quarter of an hour, twenty minutes, just getting my breath back"* (19).

Alison described vividly the problem of trying to cook her own meals and the consequences of this, *"I'm so exhausted, by the time you've done your tea you can't eat it...that's when you start losing weight you see"* (400). In addition, she said that having COPD, and the medication she needed to take, had caused her to lose her appetite, *"...you don't have your appetite so you've lost weight then you lose all your muscle and, with all the antibiotics and you don't taste your food the same"* (405). In contrast, however, David explained that he had always enjoyed cooking and, despite being diagnosed with very severe COPD, he continued to cook his own meals whilst ensuring that he took the necessary steps to prevent him from getting too exhausted. He said, *"I've always liked cooking...it's not as straightforward now because I could be out of breath half way through it but I just...find a chair and sit down for a few minutes or have a quick blast on the nebulizer and then...go back to it"* (523). He continued by talking about how he prepared large amounts of his favourite dishes and soups and freezes individual portions so that he can use the microwave to have a meal readily available when he came home from work. He also stressed that he preferred to cook from scratch so that he knew what ingredients were going into his meals and, despite his physical problems, took steps to ensure that his meals were nourishing and enjoyable.

Some expressed regret that they were unable to do things they used to be able to do. David, for example missed the time he spent socially with his wife, *"I used to like walking around the shops with my wife when she was alive, we both enjoyed that. It's hard, I can't do that anymore..."* (81). For this individual, his loss of physical ability, due to COPD, was an additional loss occurring at a time when he was experiencing a bereavement. He referred to the loss of his wife frequently during the interview and, although she had passed away approximately two years before the time of the interview, she was, unsurprisingly, still a significant part of the narrative.

Other specific activities of daily living, such as maintaining the home and garden were important to some interviewees and, for two of the participants, the data suggested an element of regret about not being able to maintain the standards that they have set for themselves. Alison said, *"I can't do my bed, I can't Hoover...I can't use polish so much...recycle, take my bins out. There's not a lot I can do really"* (301) and Elsie missed being able to do the gardening and decorating that she used to enjoy, *"I love gardening...I now sit and direct a gardener...I would like to do some decorating...I can't"* (162). Harriet said that, *"...the typical day is the general erm, housewife's day really"* (14) but added that she took much longer to do the chores since she was diagnosed with emphysema and that she had help from her granddaughter to do the ironing.

Sporting activities were also discussed in the interviews and some individuals in the COPD group had been particularly active in this respect before the onset of their condition. George said, *"I was pretty keen on sport...I ran a bit...I used to swim a lot"* (138). Similarly, Bruce talked about the loss of his ability to go running in the way he had before, *"Nowadays, you see, I can't run any distance at all...because I get out of breath and you think 'that's a bit limiting really'"* (280). However, both of these individuals had found ways to continue to exercise within the constraints brought about by their illness. George had his own gym equipment, which he used regularly, and played crown green bowls, while Bruce continued to go to the gym and carry out his own adapted exercise regime. The importance of keeping up with exercise to prevent deconditioning had been stressed to both Bruce and George, when they attended a Pulmonary Rehabilitation (PR) course but additionally, they expressed an innate desire to maintain a good level of physical functioning in order to keep as healthy as possible. George said, *"Your general fitness is a factor in, well it helps anything, doesn't it...any problem you've got?"* (368). In this way, both were able to reduce the effects of their loss of functional capacity.

4.2.2.2 Loss of employment/role/identity

A loss of ability to make a recognizable contribution to a workforce or to a relationship came across as being a concern for some. However, not all of the people in the COPD group had retired from work because of COPD. Harriet had taken early retirement in her fifties, several years before their COPD was diagnosed and Clive said that he had difficulty finding work in their chosen trade some years ago but Alison and David attributed their loss of employment directly to their respiratory condition. Both of these individuals had jobs that involved communicating with the public and had found their work difficult due to their breathlessness.

Alison recounted why she took early retirement at fifty on the grounds of ill health, *"So, it's talking all the time then coughing, especially if you've got an infection. I was off more and more"* (560). Similarly, David described the difficulties that had caused him to work reduced hours and, eventually, to apply for early retirement on medical grounds. He said, *"If you're talking, your body's not getting enough oxygen... it's very tiring because...when you've got COPD, the way your lung is, your body actually works twice as hard as anybody else's would do...when I was doing...eight hours at work...(it was) like doing double"* (48).

For some, there was a sense that a lifestyle change was being inflicted upon them and they had found it difficult to get used to. In the case of Clive, it was the change in his sense of identity and a loss of role that had come about due to the limitations imposed upon him by his condition that he wanted to talk about. He said, *"When I was twenty-one, I was a self-employed bricklayer, I played semi-professional football, I used to do the doors and life was just one long laugh...there'll be none of that now"* (117), *"I mean my wife's doing more and more...it used to always be me because I was at home. I did all the tea and everything would be ready when they got home but now they're doing it all, when they come in"* (256). In saying that life used to be *"one long laugh"* but *"there'd be none of that now"*, he gave the impression that, not only had he lost the physical attributes required to play sport and to carry out manual labour, but also, because of this loss, his life was no longer pleasurable. Feelings of regret also came through when talking about how he now had to rely on his wife to take a bigger share of the household chores.

This theme of loss of role etc. had an outlying theme of loss of education. Although several of the COPD group talked about experiencing respiratory illness as a child, only one person, Alison, spoke about how she had lost out in terms of education as a result. This was therefore not a common theme in the data but was significant in terms of its importance to one of the participants. Alison described how she missed a great deal of schooling between September and March each year due to untreated chest infections. When asked if she thought she might have gone into different employment, had she not missed so much of her education, she spoke poignantly of their mother's reaction to her educational prospects, *"I never went for my eleven plus because my mum said it wasn't worth the paper and the pencil"* (589). She did, however add that, although she could not do maths, she now enjoyed solving crossword puzzles and was proud of the fact that she had continued to learn, to the extent that her grandchildren regarded her as being knowledgeable.

4.2.2.3 Loss of independence

Some of the interviewees expressed a loss of independence, in different ways. This could be in terms of having to ask for help with personal care, such as Ian whose wife helped him to carry out his chest clearance each morning but, for most, it was explained in terms of having to ask help to carry out domestic chores. Alison, for example, was no longer able to do her own shopping but had adapted to this by shopping on the internet and had to have it delivered to her daughter's house. Alison explained *"I've not been to the supermarket or shopping since, for two years...I get it delivered...to my daughter's"* (35). Similarly, Harriet found it too tiring to go to the supermarket but paid her granddaughter to do this for them, although she still took her car to shop locally.

There was little said by the interviewees to indicate how they actually felt about this loss of independence and most appeared to be resigned to having to accept help if it meant that things were done. Only David, when talking about going on holiday with his Mum *"...for the first time since I was twelve"* (644) laughed nervously as if he

sensed some embarrassment in giving the impression that he may be unable to go away alone and that he had reverted to a childlike dependence.

4.2.2.4 Loss of friends/social life

The reasons for the loss of all or some aspects of participants' social lives were highly individual, with some citing physical symptoms such as breathlessness or lethargy as being problematic, whilst others spoke about the psychological difficulties of anxiety, panic or the fear of catching an infection.

Some interviewees said that they now had no social life at all. For example, David simply said, *"I don't have any social life"* (52). Others were limited by physical restrictions such as Alison, who said, when talking about being a member of the Breathe Easy group, *"I couldn't walk about so the trips are out"* (288). These were something she had enjoyed in her earlier years with the group and she also spoke with an air of resignation, about being with a small group of friends who had organized their own day trips at one time but were now unable to take part in these activities.

Participants regretted not being able to do different things, such as going out in the car or being able to walk far. Alison reported that, *"I was out every day in the car and everything but these last four years it's been a downward"* (30). Her use of the expression "a downward" indicated that she saw this as something that marked a reduction in her quality of life.

Clive gave a mixed impression as far as his social activities were concerned. He talked about not being able to go out walking because of breathlessness and said he had stayed in the hotel while his wife went to the Christmas Markets in Manchester. He said, *"...it was cold and wet...and I just didn't feel like it. So they just had a wander round on her own and I stayed in the hotel"* (338). He also referred to not being able to go up the road with the nurse because of the bad weather but later, when recalling this incident, said, *"...it was more panic than...than anxiety"* (320). Furthermore, when asked if he would like to go to talk to someone about this, he replied that he

would prefer for someone to come to his home, *"I'd rather someone came here...I'm in my own little domain here"* (324). He added that he was still able to go out with assistance, *"I still go out but I mean it's either a taxi...or somebody picks us up from the front door"* (60). The fact that, despite his problems getting out of the house, he was planning a foreign holiday with his wife for the following year was an interesting contradiction. His situation was of particular interest in terms of the interaction between breathlessness due to COPD, anxiety and panic.

Studies have been carried out exploring the affective components of dyspnoea (breathlessness). The cognitive model of panic (Clark, 1986; Sutton, 1999) proposed that panic arises from catastrophic misinterpretation of bodily sensations, such as dyspnoea. This led to other studies suggesting that a patient's emotional reaction to a sense of breathlessness exacerbates this perception, resulting in the "anxiety-dyspnoea-anxiety cycle" (Carrieri-Kohlman et al, 2010). Clive's interview contained data that indicated some affective component in his reluctance to go out and it would have been valuable to explore this relationship in more detail with reference to the existing literature, had the time permitted.

Elsie also talked about experiencing panic and was unable to leave the house alone. However, Elsie's problems with panic attacks predated her diagnosis of COPD, although she said, *"...the panic attacks and the breathing play off one another"* (350). She talked about the loss of spontaneity she experienced, *"A combination of both the COPD and the panic attacks, I can't spontaneously go and do something anymore"* (194).

For others, it was a fear of contracting an infection that prevented them from continuing with social activities and this was a particular problem for George who no longer felt able to attend church, *"I'm frightened of going in the winter...picking things up...even at the luncheon club...you can pick something up quite easy, can't you?"* (179). Similarly, Alison said she did not feel able to mix with other people socially during the winter months, *"you don't do much this time of the year...it's the worst for infections"* (9). However, Alison talked about maintaining daily contact with family and friends by telephone and the use of Skype, which therefore mitigated the social loss to some extent.

4.2.2.5 Financial loss/gain

It was surprising to find that few of the patients wanted to talk about the financial burden of having COPD and, when they did, it was in specific terms. Two patients mentioned the cost of medication that they had bought to supplement that provided by the NHS. David had paid for nebulizers to keep at work, or at various other locations, in order that he would not be concerned about being unwell without having his medication in easy reach, while Alison had purchased oxygen to take on a cruise. David said, *"I bought, all the nebulizers are my own...the one I've got here...that was £109, I bought that. That (pocket nebulizer) was about ninety-six, I bought that. And the one upstairs, I've actually got one of those in my office drawer at work as well, so I was covered at work...I bought that one as well. And there's another one I've got here, which is spare, which is the first one I originally bought...at the time it was quicker to get my own"* (586).

Alison recounted how she had spent a great deal of money on oxygen cylinders for her holiday, *"when I went on a cruise last year because with my mum dying she left us some money, so I treated my daughters to a cruise. So I had to buy...that, that was four hundred and ninety (pounds) and then those are twenty pound each"* (550). These two interviewees gave the impression that they regarded this extra expense as an inconvenience but did not appear to feel it was a matter for complaint.

Bruce and Clive both talked about the increased cost of travel insurance as COPD patients. Bruce wanted to visit his son abroad, *"Next year, if I go, I'll have to pay an enormous amount of insurance, medical insurance"* (277). Clive was investigating the cost involved in going on holiday with his wife, *"...we've also been on to some companies about insurances...and the cheapest one we've found was twelve months' cover for, I think it was a hundred and eighty"* (352).

Surprisingly, on the other hand, some people talked of unexpected financial benefits when they had to leave work. Alison, for example talked about how, although she was initially reluctant to do so as she believed she would suffer financially, she was persuaded to take early retirement on medical grounds. She added, *"...eventually, I*

took medical...I was better off than when I was working so...because then I got DLA" (578).

Similarly, Clive was both surprised and pleased to find that the benefits he received relieved the perceived financial burden on his wife as the only wage earner in the household. He reported that, *"We got awarded erm, (pause) living allowance or something...and that does ease it up on (partner)"* (253). He expanded on this by saying, *"Funnily enough I mean all the time I've been a self-employed bricklayer I er, I've never had money at Christmas...and now I have...plus my (partner)s taking early retirement and they're going to pick a few bob up"* (350).

In George's case, his wife had not wanted him to leave work as she was concerned about the financial implications but he felt that he had made the right decision at the time. He summed up the financial benefits of their early retirement on health grounds, by saying, *"So it worked out all right for me...golden handshake, thirty thousand quid"* (578).

One interviewee was appreciative of the fact that they were independently financially secure and able to use money to improve their quality of life to some extent whilst still recognizing the difficulties that others may have to face. Elsie explained, *"I don't have to rely on benefits...which I'm sure in lots of cases...adds to how bad you feel. I haven't got to worry about bunging up the heating or getting extra fluids down me or suddenly having to eat a lot of fruit. I can afford it...I know I am lucky in that way"* (229). Therefore, this participant and those who were able to buy their own additional medication, have been able to ensure they have what they require to support themselves in poor health. This is something that the NHS and existing social services are unable to do to this extent.

To summarise, although all of the participants in the COPD group experienced some degree of loss in terms of physical impairment, the effect this loss had upon the individual person depended largely on what they regarded as important in terms of their own particular interests and priorities. Some experienced a change in how they regarded themselves in terms of role or status, either with respect to the necessity to retire from employment or being unable to provide support to their family. Loss

of independence was described in terms of seeking or accepting help from family or outside agencies. Loss of social life was talked about but, in some cases, COPD was not cited as the only reason and one interviewee actually regarded having COPD as being a convenient way of declining social invitations. Financially, although the extra cost of medication was cited, there was little evidence, in this sample, of financial problems due to having COPD and three of the interviewees actually regarded themselves as being financially more secure after leaving work.

Although the participants did not talk directly about the emotional aspects of loss, it was apparent from the importance they ascribed to certain activities what specific type of loss was most keenly felt by each individual.

4.2.3 Experience of the healthcare system

The patients' experience of the healthcare system was discussed in every interview in the COPD group. Individual experiences varied in frequency, type of healthcare professional seen, form of consultation and satisfaction with the care provided.

4.2.3.1 Experience of primary care

The management of long-term conditions, in primary care in particular, has undergone changes over the last ten years. The introduction of the Quality and Outcomes Framework (QOF) in 2004 led to changes in the way that the monitoring and treatment of long-term conditions is carried out in GP surgeries. QOF is a method of pay for performance in primary care, which is dependent on fulfilling certain targets and guidelines for patient care. One result of the application of the QOF guidelines is that people with certain long-term conditions such as COPD have regular review appointments, usually with the practice nurse, meaning that the progression of the condition is monitored and potential problems are highlighted at an early stage. However, individuals in this sample showed little appreciation of this aspect of their care. Florence said that *"I should have gone last week to see (name of practice nurse)...but I've been mithered a lot just recently...and that's what made me miss the*

appointment.” (164) also George reported that “I suppose I should go (to see the practice nurse)...there’s no hurry” and “(practice nurse)...asks me how I am and what have you...just routine stuff.” (214).

The quality of primary care was measured, by some, in terms of how easy it was to obtain help in a crisis rather than by how effective the overall care package was for their condition. Elsie said, *“I’ve got a bloody good doctor’s surgery...I mean if I rang up now...and I said I needed to speak to a doctor...within an hour, a doctor will be on the phone”* (237). Similarly, Florence added, *“But I just ring the GP up now and say ‘I’ve got a chest infection, can you leave me a prescription?’”* (406) and *“...he’ll just leave me a prescription...for antibiotics.”* (477).

One interviewee (George) praised his GP highly for his positive input into an application for early retirement. He said, *“I got (GP) to write a super letter”* (521) and *“I couldn’t have written it better myself”* (526).

These patients appreciated their GPs for the assistance they could provide when needed, for whatever reason. They valued the relationship they had with their doctor and there was an expectation that he, or she, would respond favourably to their requests. This perception, however, was challenged in situations where an unfamiliar clinician had been called upon to treat the patient. For example, in the early stages of their respiratory problems George received a diagnosis of emphysema, which was subsequently withdrawn by a respiratory consultant, but caused him distress at the time. He recalled, *“...the asthma got pretty bad...a stand-in doctor came to see me...‘You’ve got the beginnings of emphysema’”* (57) and *“well, that was an emotive term, like cancer...to me...because wife’s uncle had died aged about fifty from emphysema”* (63). Similarly, Elsie said that she was upset by a young locum who wanted to do a home visit rather than accept her self-diagnosis. Her account was as follows, *“...he said, ‘I’m the doctor’...I went ‘And I’m the patient...who knows their illness very well’ but he did do the home visit...and he did agree with me”* (560).

The concept of the patient being an expert in their own condition, often in conjunction with the information and support they receive from the hospital, arose

in other interviews. Alison, for example, stated that *"I self-medicate anyway...I don't see the GP, because they don't know anything anyway"* (214).

Bruce talked about carrying out his own research into his condition and when he found that his health deteriorated in the few weeks following his giving up smoking, he looked into the effects of withdrawing from nicotine. He explained the findings of his research on the internet. He said, *"...there's another thing...nicotine is very similar to some bronchodilators...the chemical formula is very similar...whether it has the same effect, I've no idea. I've asked a few doctors they've no idea either"* (212). This individual had also decided to cease taking his medication as a result of his own investigations into the possible side effects, despite being diagnosed with severe COPD. He found that *"...it affects some animals eyes...and no, nothing about humans (in the information) and I think 'that is worrying me a bit'....I'd already packed (inhaler) up...but I thought 'That's another reason not to go back on it again'"* (591).

Despite their interest in finding out about their condition, no one in the study said that they had attended an "Expert Patient" programme. These courses typically comprise of two sessions per week over a period of six weeks and are designed to help those living with long-term conditions to learn new skills to manage their condition better and to be able to take more control from day to day. Attendance on such a course could have enabled them to learn more about COPD within a structured framework and could help to reduce the possibility of encountering misleading or erroneous information in the course of their independent research. These courses are available in the area in which all but one of the study participants were registered as patients but it is not known whether this information was made available to them through the healthcare professionals with whom they had contact. One of the healthcare professionals, who worked in a pulmonary rehabilitation (PR) group, did say that it was possible for people to attend the Expert Patient programmes following PR, but there was no evidence in this study of any of the people in the COPD group having done so.

Very little data emerged from the interviews concerning opportunities the individuals may have had to talk about psychological or emotional concerns during a primary care consultation. Florence, however, said that she felt she could chat to the practice

nurse about things that were worrying her (429) and David and Elsie had both received Cognitive Behavioural Therapy but neither felt that it had been beneficial in the long-term. David stopped the treatment because of *“the bits of paperwork you get after”* and *“my wife passed away as well”* (230) and Elsie felt that it *“...it helped considerably for a while but of course it stops”* because *“I’ve had panic attacks since I was young...so I didn’t expect it to be over within a few weeks’ treatment”* (342).

It was suggested in one of the interviews with healthcare professionals that there is a shortage of therapists to whom patients can be referred and that, as a result, GPs tend to prescribe anti-depressants instead. David, when asked if he was having any help for his anxiety and depression replied that he was on medication for those, in addition to the medication he already took for his multimorbidities (225). However, Alison reported that she had been offered tablets for depression but refused them because *“...I was on Valium after I had my daughter...and it took me eighteen months to get off them”* (455). This response may suggest that Alison had not been adequately informed of the alternative treatments now available. It is possible however that, although a talking therapy may be more beneficial to their patients, some healthcare professionals are prescribing antidepressants because of the lack of availability of suitably trained therapists.

4.2.3.2 Experience of secondary care

There was considerable variation in the COPD group’s experiences of secondary care. Some regarded the hospital as their main source of support, others preferred to see their GP regularly and have infrequent reviews with a consultant and some attended both primary and secondary care on a regular basis. Alison relied on the advice of the hospital respiratory team rather than their GP: *“Well, if I feel ill I’ll just phone...the hospital and say ‘I want an appointment’...They say ‘If you need to be seen sooner, you know, to phone up’”* (494). Florence, on the other hand, had her COPD monitored by the local health centre: *“I do go for check-ups...to the Doctors, clinic, you know”* (152). When asked about hospital attendance, Florence found it difficult to recall whether she attended the respiratory department at all as she had so many

appointments for other medical conditions: *"...no, I don't think I do, no I don't. I have that many hospital appointments sometimes, I don't know"* (157). In addition to having spoken highly of the care they received in their GP practice, Elsie also felt that the care she received at the hospital was very good: *"I rate (local hospital) something amazing"* (295). She continued, *"I go to the chest clinic there every six months to see (respiratory consultant), the nurses there are all great, the girls in the spirometry...the PR girls. I just can't find anything to complain about"* (311).

At the time of data collection, two of the interviewees, Alison and David, had recently changed from attending their local hospital to a different one with the reputation for being a centre of excellence in respiratory care. This meant both of them travelling a greater distance to attend appointments but they said that this was worthwhile. Alison praised the new hospital highly and said that it *"...gave me two years (of active life) because, up until I went there, I never went out of the house"* (413). Similarly, David credited the same hospital with his present state of optimism *"Much more positive things are happening at (new hospital)"* (245).

All the people in the COPD group, talked about their experiences as patients in the healthcare system and the data obtained for this theme comprised largely of their experiences of consultations in primary or secondary care. Three individuals, however, had narratives of interest that were quite specific to their own experiences and separate from the rest of the data in this section.

Firstly, Clive spoke about how he discovered that he had been diagnosed with COPD: *"Well, it was only by accident that I found out. I was in hospital and I just saw it on my record and didn't even know what it was"* (88). He continued to say that, as a result of finding out in this way, it was some time before He heard, from their own GP, the details concerning their condition and also that they were unaware of the implications of continuing to smoke during that period.

Although Clive's experience took place within the last two or three years, Florence recounted how she was introduced to smoking whilst in hospital after giving birth to her daughter more than thirty years ago. *"I never smoked till after I had my daughter...I was in hospital...they had you in for ten days at that time and the other*

women were going to the toilets for a smoke” (284). Despite this event having taken place many years ago, and being unlikely to happen now, it was an incident that was still an important part of Florence’s narrative and one that has consequences affecting her health today.

Thirdly, Bruce’s notable experience was as part of the Patient Representative Group at his local hospital. He spoke strongly about his frustration and how he thought that his views, and those of other representatives, were not being taken into consideration by the committee members. *“I think I’m wasting my time...I am becoming more and more certain that they are only asking those people to join these committees because then they can say they’re consulting with the public...they take no bloody notice whatsoever of what those people say, in my opinion” (638).*

4.2.3.3 Experience of pulmonary rehabilitation

Several members of the COPD group had been on a course of pulmonary rehabilitation (PR) and Elsie was attending one at the time of the interview. Despite suffering from panic attacks and being unable to leave the house alone, she said, *“I think it’s an amazing thing and everybody should get the chance to go on it” (778).* She added that it provided *“...a chance of some positivity instead of everything being so negative...and things are negative when you’ve got COPD...because there is no cure” (792).* Bruce agreed that PR was beneficial. In his words, *“The only thing I would say about Pulmonary Rehabilitation is ‘I found it bleeding excellent’...it’s one of the few things supplied by the National Health which I found extremely good...and it certainly worked for me” (375).* Elsie felt that PR was money well spent in terms of NHS funding and was strongly critical of other ways in which the healthcare system used their resources. She proclaimed, *“...stop wasting money on silly things that won’t help...on trying to make people diet who want to be fat...and help the people who want to do something to help themselves” (816).* The social aspect of PR was regarded as beneficial for some individuals. For example, Alison reported, *“Pulmonary rehab...I’ve been there twice...that’s where you meet lots of friends as well” (234).*

Harriet said that she would not take up the offer of attending a PR course *"I wouldn't have agreed anyway...if it had been put to me"* (407). However, of those who had started a course of PR in the past, only one person, Clive, said that he stopped because he did not feel it was helping him and, in hindsight, he said, *"I must admit I was a bit erm, what can I say, complacent. Because at the time I didn't feel as bad as what I do now"* (213).

4.2.3.4 Experience of emergency care

Emergency care was regarded as an important part of their healthcare for several of the COPD group and none of the interviewees spoke of experiencing unsatisfactory service in this respect. When asked if they had needed to call emergency services in the previous year, David said, *"I think I phoned for an ambulance about sixteen times and out of that I think there was ten or eleven actual admissions"* (170). David, in particular, spoke in detail about the breathlessness he experienced, the fear he felt in these emergencies and the importance of the prompt arrival of the paramedics. *"...but then you're in there then, not able to breathe, waiting for a paramedic to come round and it's just so...so frightening"* (368). Clive also had reason to contact the emergency services after being acutely ill during the night. As in David's case, it was Clive's wife who called for the ambulance *"When my wife got up...and saw the state I was in down here, she phoned an ambulance straight away and they took me in"* (185).

In cases such as those above, the individuals involved and their relatives felt that they had no option but to call an ambulance, however, in situations where people with COPD required medical attention urgently but did not regard it to be a life-threatening situation, different experiences were recounted. Clive had experience of calling the COPD nurses who contacted the doctor for him *"...well I fell three times in the day the third time was in the kitchen...as I was on my way to bed and erm (pause) we got a doctor out. Phoned the COPD (nurses) and they sent me a doctor out who admitted me straight away into hospital so there was no mither at all about that"* (276). Elsie said that, in her opinion, *"...even the emergency doctor service here is*

pretty good" (324). Florence, as related above, called the GP directly for a prescription if she felt she had a chest infection and Alison would contact the hospital respiratory department. Such variation in patient choice was interesting and it would appear that there is no overall strategy for emergency contact that applies to all people with COPD in this particular healthcare area.

However, none of the interviewees said that they had trouble in contacting a healthcare professional when required, although George did reminisce about the early days of his illness (around thirty years ago) when GPs did home visits "*...they'd come out then...well, you can get an emergency doctor now, you've got to be pretty bad though, haven't you?*" (83). George's observation provides an example of the changes in healthcare during the lifetimes of the people in the COPD group.

4.2.4 Locus of control

Locus of control (LOC) is a concept that originated with Julian Rotter's (1954) social learning theory. Rotter (1954) stated that the likelihood of a behaviour being carried out is dependent on both the extent to which the actor believes the action will lead to a particular reinforcement and the perceived value of that reinforcement. Rotter (1966) later proposed a distinction between 'internals' who believe that events are consequences of their own actions, and 'externals' who believe that events are unrelated to their actions.

Wallston, Wallston and DeVellis (1978) applied Rotter's theory of LOC to health-related behaviours and developed a scale, the Multidimensional Health Locus of Control (MHLC) scale, to measure health-specific LOC beliefs along three dimensions. These dimensions measure the extent to which a person believes that their health is a result of either their own actions, under the control of powerful others or due to fate and/or chance. However, Wallston (1992) found little evidence linking Health-related LOC (HRLC) to health behaviour. A later study by Norman et al. (1998) found all three dimensions on the MHLC scale to be correlated with health behaviour but suggested that other expectancy beliefs needed to be taken into consideration.

In the present study, the theme of locus of control (LOC) was illustrated in the context of several topics where individuals spoke about aspects of their daily life and health in terms of being influenced by their own actions or by influences external to themselves.

4.2.4.1 Medication Use

Although all but one person, Bruce, in the COPD group took regular medication for their condition, there was notable variation in the type and amount of medication used. Some of this variation could be due to the severity of the condition but, as no definitive measure of severity was recorded in this study, this cannot be assumed. The theme of medication use was again one where individual differences were apparent.

Despite having been diagnosed with severe COPD, Bruce had reached the conclusion that: *"Taking medication has positives and negatives, I see no positives whatsoever"* (343). As noted above, research they had done on the internet into possible side effects of medication they had taken in the past had also led them to believe that it could be detrimental to their health.

This could be regarded as an example of his internal locus of control in that Bruce chooses to make his own decisions about his treatment. This view contrasted sharply with those of others in the study, some of whom expressed a more external locus of control concerning the control of powerful others, in this case healthcare professionals who prescribed their medication. Harriet, for example, accepted the medication regime prescribed by her consultant without question: *"...then I see the doctor, consultant, and then he says 'Stay on the medication you're already'"* (183) and *"I've just accepted it, you know"* (330). Ian had been recently diagnosed and stated, *"I believe in drugs"* (30). He felt that steroid treatment in particular was valuable in enabling him to feel well enough to return to work and carry out his other activities. George also spoke of his regular medication as something that he relies upon *"...it's great...and it keeps me in order"* (224).

However, for some people in the study, there was concern that the medication they relied upon was no longer as effective as it had been. David, for example, said, *"Yeah, but they (inhalers) don't seem to work so much these days now it's going that severe"* (453). Another concern for several of the people in the COPD group was their experience of side effects from their medication. Here again, individuals were expressing a sense of resignation in that they were being subjected to issues of ill health over which they had no control. Alison spoke in detail about this *"...it affects your stomach...then you've got the hiatus hernia because it gives you gastric reflux...so there's the steroid affecting your bones so you've got another tablet for your bones. So one starts another thing, it's one after the other. So it helps you with one thing, but then it gives you...something else"* (107). Similarly, David talked about how his medication taken for COPD affected his other medical problems: *"...I've got it (prednisolone) down to ten milligrams...any lower and I go worse...because underactive thyroids put weight on, which is what I've got. And prednisolone puts weight on...and plus excess water retention...so I'm battling three things there...which all puts strain on the lungs and heart"* (658). David's behaviour in reducing his medication to the lowest level at which he felt their condition was stabilised, would appear to indicate an internal locus of control.

Another way in which people were able to exert some control over their medication was in having an emergency pack available for them to use in the case of an exacerbation. Alison was confident in her ability to recognize when her symptoms indicated that it was necessary to use them *"I've got two lots of different antibiotics and steroids and it's how I wake up in the morning, and I know myself"* (190). Harriet also was happy to decide when to use her emergency antibiotics *"I've always got to have (antibiotic)...in case I start coughing...if it's not just my short of breath...I know myself"* (218). Both of these people expressed their certainty in deciding when this medication was required although this contrasts with the views of one of the healthcare professionals in the study who felt that his patients still needed professional advice before embarking on a course of treatment.

The use of oxygen therapy, and subsequent dependency on it shown by some individuals, was also something that varied considerably between patients in the

study. For example, Alison used oxygen frequently. She reported, *"Well I mean it used to be about fifteen minutes when I first started with it, but I've got to go nearly, sometimes it can be about ten hours"* (393) and *"...I'm using it more because even going out I've got to, walking around, because I couldn't have a bath without oxygen"* (396). However, David was not given oxygen to use at home despite his frequent use of other forms of medication. He had been told that it could be dangerous for him: *"...because my body is used to a lower amount of oxygen, if I have too much of it, I can also overdose on oxygen...and that could give me brain damage"* (199).

David did show internal locus of control in his behaviour as he had purchased a pocket nebulizer for use outside the home and found this very beneficial. He explained why he felt this was necessary, *"So, it's any time I go out or even if I just go over to (supermarket) I still take that...I might be fine when I leave here...but you never know in (supermarket) I could turn for the worst"* (625). In addition, he carries his empty medication packs with him when he leaves the house, in case of emergency, to show what medication he takes, an initiative that is appreciated by healthcare professionals. *"In fact the doctors at the hospital and the pharmacists at the hospital say that's a brilliant idea...and they recognize stuff straight away that way"* (612).

Despite the overall acceptance of their medication regimes by the group, two individuals had taken control of their treatment, to some extent, in seeking out alternative therapies and this emerged as an outlying theme. Firstly, Elsie had taken a psychological approach *"My son taught me some meditation techniques"* (352).

Secondly, George, who was using a hand-held device that his son-in-law had seen, advertised to exercise the lungs and therefore improve breathing, and he felt that it had improved his quality of life. He spoke enthusiastically about how much it had helped him: *"Before I started taking that I got all this coughing and spluttering I did for a few hours every morning, it just took my energy"* (311) and *"yeah, I would say it's worth the money"* (1030). Also, despite the cynical attitude of his friend, who told him that it was 'all in the mind', George felt that his regular dose of garlic capsules was beneficial: *"I've been having one a day of those...for twenty years...I read it in the paper...particularly good...to keep your lungs in order"* (262).

4.2.4.2 Support

Several of the interviewees spoke about the support they get from family, both practically and emotionally. They were appreciative of what their families did for them. Harriet was particularly appreciative of the support she received: *"What I can't do of course the children do...it's lovely to have them"* (247). However, she stressed that she paid her granddaughter to do shopping and ironing for her *"I pay her, you see...this is her working for me"* (28), thereby retaining a certain amount of control. Similarly, Elsie talked about how she could ask her son and daughter for help on her own terms: *"They're both very good to me...neither of them mither me...but they're there if I want them"* (719).

There was a sense of inevitability in some of the conversations, this was illustrated expressions such as *"of course"* and *"they're there if I want them"*, used in the quotations above, which gave the impression that there was a realistic understanding that assistance would naturally come from within the family.

However, in an emergency situation, the dynamics of the relationships within the family appear to change and, despite the need to retain independence, Harriet was happy for her family to take control of the situation in such an event: *"My daughter came...and she says 'Are you all right?'" so I says 'No, I don't feel good at all'. So (daughter) just gets on the phone and I get the erm, GP's partner...'I can see pneumonia'"* (355).

On the other hand, David talked about how he plans for times when he may feel too unwell to go downstairs *"I always have cordial made up, in bottles up there, so I've got cordial, and for the times when I can't come down, because I have bad days where I can't come down at all. I have breakfast cereal bars up there...before now I've gone three days living on them and cordial"* (550). He then continued by recounting how friends and relatives reacted to his independence, *"People tell me off, next door do, the lady up the road does, step children do. Tell me off, they say, 'Why didn't you phone me up if you can't get down and cook?'...I said 'Well, I managed, I'm all right'"* (556). However, in the case of a crisis concerning his health, he reluctantly accepted that he also needed external help from his wife, *"I'd been struggling all night*

breathing, my wife wanted to phone for an ambulance and I said 'no' then came morning...I actually struggled coming downstairs ...I couldn't put two words in a sentence and I had to crawl up them stairs and it was like fighting for my life crawling back up there. She phoned for an ambulance" (121). Since the death of his wife, David has registered with an emergency care company *"I've got Carecall fitted now...I had to, and a key safe outside"* (340). This is an example of someone who could be said to have an external locus of control in that their behaviour indicates that they are seeking help from outside agencies and yet their foresight and planning would indicate that they are taking control of their situation and therefore has an internal locus of control in psychological terms.

Although most of the interviewees referred to the assistance that they obtained from their families, other means of support that individual people talked about in the interviews included friends, neighbours and the church. For Alison there were friends who were in a similar situation, experiencing physical limitations due to ill health, with whom she found comfort. She said, *"More my friends now, is the same situation...like the lung, we've all got the same thing...they've got bronchiectasis or emphysema...so if we all go out for a day, if we go out in summer, we know how far and how limited we can you know, what we can do"* (48).

For Elsie, support came from knowing she had good neighbours; something she attributes to good luck *"And I have wonderful neighbours...who are also there should I need any help...so I am, as I said, somewhat luckier than most people"* (725).

Alison and George both talked about how they used to go to church, but now felt they were unable to attend. The importance they attached to this as a means of support suggested that it should be an outlying theme. Alison said that she suffered ill effects from the incense used in church and George was concerned about the possibility of picking up an infection. Alison said *"I found it worse when I went to the church on Sunday....you know, with the incense"* (177). Moreover, George explained *"Yeah, (I was) very much involved. But I'm not now because I, I don't go...I might pick it up in summer...it's (sighs), I'm frightened in a word...of going in winter...picking things up, yeah...you know, you can pick something up quite easy can't you?"* (181). In contrast, Harriet, however, was still a regular church attender, member of the

church choir and she enjoyed taking part in an art class which was run by another church member.

One particularly interesting comment by George illustrated that his locus of control regarding his health was external in that he believed that illness was something under God's direction. *"He uses illness to, well, to get things done if you like, you know...shouldn't have to do but you know, our stubborn, stubborn nature"* (748). He revealed that he had been "saved again" (740) around the time when his illness started and his partner also became ill with a progressive disease, which has left her wheelchair bound. Throughout the interview, George referred periodically to his religious beliefs and spoke of how he had found the answers to their questions in the bible. However, despite his strong beliefs, he was still very active in trying to improve his own health by regular exercise with his own gym equipment and seeking help from both traditional healthcare sources and alternative remedies.

Breathe Easy is a support group for people with chronic lung conditions. It is run by volunteers, under the auspices of the British Lung Foundation, and groups arrange entertainment, speakers, trips and social events. Members show an internal locus of control in seeking out self-help and becoming an active part of a support group and those who did attend Breathe Easy expressed strong feelings about it. It therefore emerged as an outlying theme related to the theme of support. However, there are those, such as Ian, who has no desire to attend a self-help group and feels it would be of no benefit to him, *"I have read about them, on noticeboards and leaflets in waiting rooms, but no, I would rather wheeze alone than along with a lot of other people"* (33).

There are also indications in the interview data, that some people who may possibly benefit from this type of support may have not received sufficient information and encouragement from healthcare professionals to enable them to make an informed decision whether or not to join such a group. For example, David said, *"No...I might have heard of it but I don't know cos there's been a lot going on in my life recently with this, and my (partner) (passing away)"* (321). Florence also dismissed the idea, *"No, I don't think I could go to meetings. It's a bit depressing, you know"* (458).

Only two of the participants in the COPD group of the study, Alison and Bruce, were regular attenders at Breathe Easy meetings. Despite indications that these particular individuals had an internal locus of control by actively seeking out and taking part in this type of self-help group, they did not appear to be gaining significant benefit from their membership. Both Alison and Bruce expressed dissatisfaction with their experiences of being members of their local Breathe Easy group.

Alison had been attending Breathe Easy for more than ten years but felt that her deteriorating condition now prevented her from going out on the organised trips and, in addition, several of the members she knew from their early years there had now left or passed away. Alison: *"...but you know it's, it's not the same, no. And they haven't got the members like they used to have...there was more members but there was more, erm, I don't know, different atmosphere"* (275).

Bruce's criticisms arose because he felt that the group no longer had a competent committee, able to carry out the day-to-day administration and organisation of the meetings. As a member of the committee, he felt that he was being required to take on an unreasonable share of the responsibility. He said, *"Is Breathe Easy a good part of my life? Unfortunately not...they want me to be chairman, they want me to be secretary, they want me to do the minutes and I can't do all those things"* (414).

These opinions, in conjunction with data from my own field notes, taken after attending Breathe Easy group monthly meetings from April 2013 to August 2014, suggest that, despite the best efforts of those who work hard to keep the group thriving, this particular group is not currently meeting the psychosocial needs of all its members.

4.2.4.3 Causes/Triggers of COPD

Smoking history was discussed in all but one of the interviews for the COPD group and attitudes to this topic were unique to each individual. Some felt that, although they had smoked, external influences had acted to trigger the development of COPD,

possibly indicating a tendency towards an external locus of control and reduction in self-blame.

For example, Alison said, *"I think I did smoke for er, for about thirty years"* (145) and *"Yeah, I did smoke for a long time. But, erm, they said I was, I didn't smoke enough, or long enough to get emphysema at forty-eight...so I think I had a weak(ness there)"* (147). David said that he had smoked roll-ups for twenty years but had been told that an injury had triggered his condition: *"...and what the doctor said is, I fell previously when we had the snow when I walked up to the top of the road. I slipped in the snow right on my side here...which banged the lung and that's what...(started it off)"* (135).

George talked angrily about how he had been affected by passive smoking in the workplace and called for a complete ban, *"I was a fairly light smoker...but, it was a smoking office...and I was always in the office so that didn't help."* (398) and *"...smoking, why the heck don't they ban it altogether?"* (391). As if to reinforce his concept of others being responsible for the effects of smoking on his health, he added the following comment: *"Sir Walter Raleigh, he wanted hanging, didn't he?"* (406).

In contrast, views expressed by Elsie would appear to indicate a tendency towards an internal locus of control. *"I knew the dangers of smoking, it is a matter of choice. I don't blame anybody...not the cigarette companies or anything like that...we've been warned for enough years that, if people carry on smoking in these days then or take up smoking even these days, they're, it's a matter of choice"* (394) and *"It's my burden, it's nobody else's...what's the point in blaming anybody for it?"* (434).

Similarly, individuals reported several different triggers for attacks of breathlessness and talked of how avoiding these triggers caused limitations in their day-to-day activities. Elsie talked about the inconvenience of having to ask someone's help to fill the car with petrol *"I needed petrol for my car at the weekend. I had to phone my daughter up to go and get my petrol...because the fumes set me off"* (203). David was unable to visit relatives and friends in their homes where the temperature may be too hot or cold *"Well, if you get cold it can set you off or if I get too warm. If I go to somebody's house it could be too warm for me in there and I can't breathe"* (631).

Alison explained that she was unable to go outside when there were high levels of air pollution or high pollen levels *"If it wasn't the pollution, it was the pollen"* (74).

In contrast to those who talked about external factors preventing them from taking part in things they previously enjoyed, Elsie claimed that her illness was used as a way of avoiding certain situations: *"It's a wonderful excuse if you don't want to do something or go somewhere!"* (360).

4.2.4.4 Progression/adjustment

Adapting to the symptoms of the disease and the changes that occur as the illness progresses was also very different in individual participants. How the people in the COPD group adjust to the progression of the disease can be related to their locus of control. Some feel more able to adjust to the changes that occur as the disease progresses whilst others find it more difficult to accept them, feeling that they have no control over their symptoms.

The severity of the disease therefore is an important consideration but is not the only contributing factor in the patient's adjustment to increasing ill health. Despite being diagnosed with severe COPD, Bruce for example, took no medication and expressed a positive outlook, seeing the need for only small adjustments in his lifestyle, such as adapting his exercise regime and spending time on his computer to keep mentally alert. Bruce: *"I look at my life now to what it would have been like without COPD I think there are only minor changes really"* (56) and *"I spend quite a lot of time...just inventing things to do on a computer. So as to keep my brain going"* (479).

David, although he had been told that his condition was life limiting, found ways to manage his activities of daily living and adapt to the constraints of his ill health. He talked about how he employs a number of strategies to take control of the progression of his condition. He spoke in detail about his state of health: *"Well, I think the left lung is running on thirty-six, thirty-seven percent...and they said if it drops any less that's when they put it on to extremely severe"* (461) and *"...basically, the way I'm going now, I've got about twelve months"* (248). Some of the strategies employed

by David to take control of his day-to-day life were described as follows: *"I've got a mobility car" (313), "I've just gone from full-time to part-time" (425)*. He had also made changes within his home: *"...I've got my electric bed up there...so, and my nebulizer's right next to my bed up there, so when I come home and get my meals, I take them upstairs...and that's it till morning...then I'm not bothered with the stairs two or three times for the bathroom, everything's up there" (539)*. In contrast, Clive displayed a less positive outlook, appeared resigned to the situation he was experiencing and expressed a more external locus of control, *"It's there, I've got it and there's not a lot I can do about it" (292)*.

A way of adapting to the changes happening as the disease progressed, employed by some interviewees in the study, was to slow down and/or reduce the physical demands on the body by doing less physical activity. It is difficult to interpret from the data how much of the reported "slowing down" is actually due to physical decline and how much is a conscious, or even unconscious, decision to reduce activity levels in order to avoid attacks of breathlessness. For example, Harriet accepted the fact that she carried out her day-to-day activities more slowly but did not explain whether this was a deliberate tactic to reduce episodes of breathlessness or whether she felt it was something that was beyond their control. She described how *"...we both take things very slowly...we have, er, quiet days" (42)* and *"...the general day works out comfortable for me...it's not a chore...I go slowly, rather than charge about like...a mad dog" (93)*. In addition, she said that she preferred to attribute her inability to carry out household tasks to her chest rather than to her age, thus indicating an external locus of control whereby something outside their control was causing her to slow down. Harriet: *"...it's much nicer to think that I can't do things because my chest won't let me...rather than I'm an old (person)" (60)*.

Similarly, other people in the sample have adjusted to life with COPD by making fewer demands on their own bodies but, again, it is unclear whether this is a conscious decision or something that has come about as an avoidance of breathlessness and has developed gradually over a period of time. In Florence's case, she felt that her breathing had improved since first being diagnosed with COPD. *"I*

think my breathing's got a lot better as I've got older...whether it's because I'm not as active as I used to be" (51) and "I don't dash about now like I used to" (54).

The way in which individuals in the study make plans for their future may give some indication of the person's locus of control. Its importance to some members of the COPD group indicated that the theme of planning for the future should be considered as an outlying theme. For several of the people in the study, the future was governed by their own plans, which they regard as being within their control but it was also affected, to a lesser or greater extent, by outside influences. Alison, for example, described her hopes concerning socialising: *"So hopefully this year we might go out. We try and meet up at different venues...we've got a new one at (church)" (79).* On the other hand, she talked about how she was considering selling her car if it becomes too difficult to get out and about: *"I won't give it (car) up yet so, see what this summer brings" (312).* The implication being that her decision whether to give up her car depends upon outside influences, in particular the weather.

Clive also gave a mixed impression of his hopes for the future. On the one hand, he talked about how the bad weather prevented them from taking a short walk up their local road but later in the interview, he spoke positively about planning a holiday to the US. He described how the COPD nurse was trying to help him to get out along their road. He remembered, *"...what we said because she (COPD nurse) said 'Well, what we're going to do is walk up the road'...and I said 'Well, the way the weather is, there's no way we're going to be messing about walking up the road in this weather'...she said 'All right' she said 'well, let's leave it until February'" (154).* He described how he was reluctant to leave the house because of the fear of breathlessness but, in contrast, he later talked about planning the holiday with his wife. He explained, *"So we are looking into that (holiday) for early next year...so we are thinking of going, we went to (resort in USA) about eight years ago...and we're thinking of going back there" (358).*

David was another participant who implied that he had mixed feelings about his future. He spoke about being on the waiting list for a lung transplant and indicated that, his future, in this respect, was in the hands of others. *"...the last time I saw him (consultant) he said, basically, the way I'm going now, I've got about twelve*

months...but, with me still being young, he asked me if I wanted to go on the transplant list...(248). He continued, "I don't live in hope, I live day by day...then there's no kick in the backside, no ups and downs. Whichever comes first, fine" (272). However, he was also making plans for those parts of his life over which he felt he had control. "...I'm in the middle of trying to sell the part I own and move...I've just gone on the housing (list)...to try and get a ground floor flat...or a bungalow...cos somewhere like this, I haven't got the quality of life I deserve" (410).

This mixed picture of interviewees' attitudes towards the future and their control over future events was particularly prevalent in their comments about the life-limiting nature of their illness. For example, Bruce talked about the contradictory information he had been given. He said that he had been given two different prognoses *"...I'm at level two (BODE scale) and that says I have, there is a four year morbidity of 20% so it looks a bit better than a predicted survival of five years, doesn't it?" (315).*

Elsie and George also both spoke of the inevitable outcome of their illness whilst indicating that they felt able to exert some degree of control over when this would come about. Elsie stressed the need for self-help *"...my attitude is, I know I'm gonna die, but I don't want to die just yet" (626) and "...don't sit back and look for a magic tablet...there isn't one...you've got it, help yourself...I mean I haven't particularly helped myself...but I'm trying" (838).* George, on the other hand, talked about being able to exert some control over his own mortality by aiming to live longer than his grandmother did: *"My grandmother died, lived till seventy-seven. So I'm aiming to at least catch up with her...it's something to...to keep you going" (464).*

4.2.5 Emotional reactions

Not all of the people in the COPD group of participants spoke openly about their emotional reactions to having COPD and to their experiences of the symptoms but those who did expressed strong emotions and some rich data came out of these narratives.

4.2.5.1 Anxiety and dyspnoea

When talking about the psychological effects of having COPD, the experience of fear came through strongly for some of the participants. David gave a particularly vivid account of his attacks of breathlessness, the loss of control and subsequent fear of death that arose in those situations. He recounted, *"...your body's shutting down...and you can't run anywhere for help, and...your body's closing down...then it's so frightening"* (352) and *"Cos every time you're trying to breathe out, your muscles are going out and...you're just on the step (short pause) of dying"* (378).

George was significantly distressed for a period of time by his initial diagnosis of emphysema, as he had known a family member pass away at a young age with the same condition and was afraid that he may experience a similar outcome. He recalled, *"...that (emphysema) was an emotive term, like cancer...because (partner's) uncle had died aged about fifty from emphysema...it really put me to bed...the psychological effect...I really did get upset and it wouldn't go away"* (63). George also talked about how the fear of catching an infection had prevented him from attending the church that he had been involved with for many years, *"....in winter...you know, you can pick something up quite easy can't you?"* (179).

On the other hand, the same interviewee later reported that having the condition had put him more in touch with his emotions and that he regarded this as a good thing. George said, *"You get very emotional. There's nothing wrong with that because I think men are a bit hard...(men) don't show enough emotion really...but I do know...flipping do now. Actually it's good in a way isn't it...it's a release"* (728).

In contrast to the concept of fear and panic arising from attacks of breathlessness, one of the interviewees, Elsie, talked about how her pre-existing panic attacks had a detrimental effect on her breathing and explained that, although she was aware that the fear was irrational, she was not able to control it. *"The panic attacks affect my COPD...I panic about not being able to breathe...even though I know nothing's going to happen, people will help...the panic attacks and the breathing play off one another"* (197). This illustrates their external locus of control in this situation as they talk about how COPD and panic attacks act together to cause their distress.

Alison indicated that she regarded depression as an inevitable consequence of having COPD and not something, like anxiety, over which she can exert control. She explained in her own words, *"Well, you're depressed. Well, I mean you're depressed. I think you do get anxious but once you've, I think you suss it out yourself. But depression is completely, you're depressed"* (421) and added, *"...once you've got it, it's a downward spiral"* (605).

4.2.5.2 Mental health care

With regards to being offered help for psychological conditions, there was a certain amount of reluctance on behalf of the patients to accept treatment. Understandably, one individual (Alison) did not want to take medication because she had had a bad experience in the past but it was unclear from the data whether she had received sufficient information as to the different types of medication available now, compared with when she was previously treated, some thirty or forty years ago. Four people in the COPD group had been offered Cognitive Behavioural therapy (CBT) but had either felt it was not appropriate for their needs, found it difficult to engage with at that particular time, or found that its positive effects did not last. For example, Alison said *"...cognitive behaviour...I had it...she came round for a while, but it's not...it doesn't, it doesn't, it's not for that (depression)...it's (for) anxiety"* (439). Similarly, Clive felt that CBT was not appropriate for his needs, saying that, *"When she (COPD nurse) came the last time it was the anxiety...and it was more panic than...anxiety"* (317). David preferred to take medication for anxiety and depression and Elsie did gain some benefit from a course of CBT but indicated that her expectations, and the outcome of the therapy, were limited. *"It (CBT) helped considerably for a while but then of course it stops...it helped up to a point with the panic but I've had the panic attacks since I was young so...I don't expect it to be over within a few weeks' treatment"* (342).

It came across in the data that it was possible that, had they been given relevant, comprehensive information and support, some of these patients may have been able to benefit from this form of psychological therapy.

Despite the lack of positive comments from people in the study regarding the benefits of psychological therapies, Elsie did say that she felt her mood had been lifted by attending a pulmonary rehabilitation (PR) course. She commented, *"...but it (PR) at least gives you chance of some positivity instead of everything being so negative...and things are negative when you've got COPD...because there is no cure...there is no cure for it"* (794).

The theme of locus of control was identified from the data in several different ways. The type and degree of support the interviewees received showed how active they were in their own care. People talked about what they felt had caused their COPD or triggered attacks of breathlessness, describing both internal and external influences. Similarly, the progression of the disease and how the person responded and adjusted to these changes was an indication of whether they had an internal or external locus of control. Their plans for the future were very much influenced by the extent to which they felt they had control over their condition and its symptoms and its future progression. When talking about the psychological effects of having COPD, interviewees often referred to losing or taking control in situations. Some of their experiences indicated a mixed picture of being in control of certain aspects of their condition, such as taking medication or planning for difficult times but then reaching a crisis point where the illness "took over" and then becoming necessary for control to be passed to an external body.

4.2.6 COPD group global theme of Individuality

Although five organising themes emerged from the data obtained from the COPD group and these themes reflect the lived experience of people with this condition, each participant expressed individual reactions and views within the themes. Despite every member of the group having been diagnosed with the same medical condition, their response to symptoms and treatment were highly individual. The above results suggest that the overriding, global, theme is one of individuality.

In terms of the organising theme of loss, although all of the participants in the COPD group had experienced some form of loss, their response to this was highly individual.

Each individual was affected by loss in some way but their individual responses determined the overall lived experience of the group. As a participant group, they expressed their own ways of experiencing and dealing with what was a common challenge. Similarly, their experiences of lifespan health indicated a commonality, in that each person felt it important to talk about their past health experiences, but it was their individual narratives that collectively determined the overall lived experience of the group.

The COPD group's experiences of the healthcare system were, in some ways, similar. All but one were taking some form of medication for the same condition and all were attending regular appointments with HCPs. However, each member of the group experienced their care differently and these individual differences combined to create the richness and depth of the data. Emotional reactions and locus of control were again illustrative of the global theme of individuality. The individual responses to these themes are particularly relevant when considering the psychosocial needs of COPD patients as a patient's locus of control and emotional reactions can influence their response to interventions and the outcomes of treatment. The implications of this global theme of individuality will therefore be explored and discussed further in the final chapter of this thesis.

Chapter 4 has examined the data from the COPD group and explored the perceptions of this participant group in terms of how their day-to-day lives are affected, both physically and emotionally, by this condition and, as a result, what their perceived needs are. Chapter 5 will therefore examine the data from the HCP group of participants in order to continue with the second objective of the study, which is: to understand how the experiences of clinicians in treating people with COPD are related to these perceived needs expressed by the patients.

CHAPTER 5 - RESULTS FOR THE HCP GROUP

This chapter outlines the results from the HCP participants. It summarises demographic data then gives a diagrammatic representation of the thematic network (Figure 5.1). The chapter then discusses the data from this group of participants in detail, exploring and summarising the thematic networks and interpreting the patterns contained within them.

5.1 Participants' demographic data (HCP group)

Ten HCPs acted as participants in this research. They are identified by the following pseudonyms: James, Karen, Linda, Mary, Naomi, Olive, Pauline, Ruth, Simon and Tom.

Table 5.1 Participants' demographic data (HCP group)

Participant	Sex (Male/Female)	Professional background
James	M	Doctor
Karen	F	Physiotherapy
Linda	F	Nursing/Psychology
Mary	F	Nursing
Naomi	F	Nursing
Olive	F	Nursing
Pauline	F	Nursing
Ruth	F	Nursing
Simon	M	Nursing
Tom	M	Physiotherapy

5.2 Results for the HCP group

Healthcare Professionals Themes

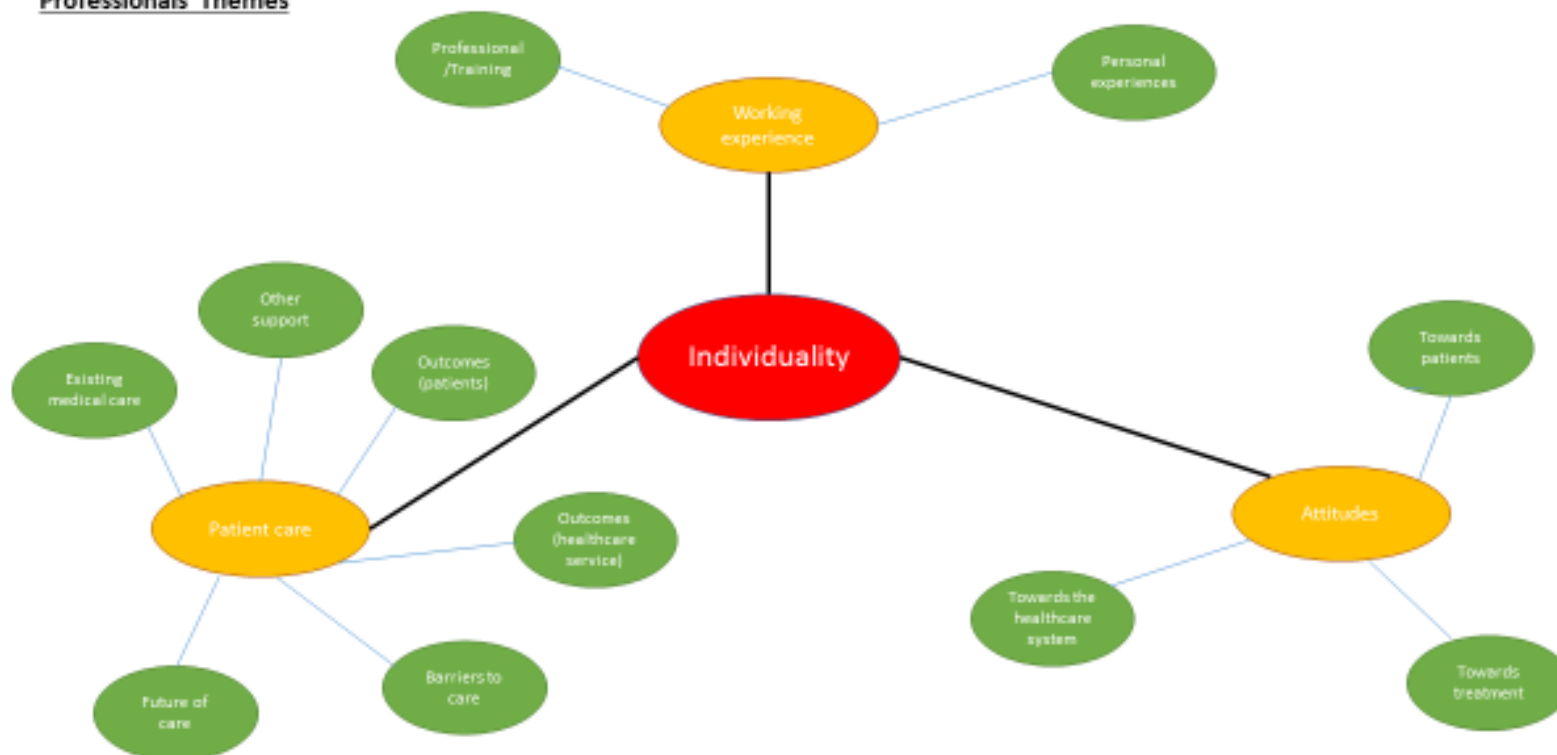


Fig 5.1 Thematic network illustration for the data from the HCP group

Three organising themes were identified from the data taken from the HCP group. These themes are summarised in Table 5.1 (below). The first of these was “Working experience” which was derived from the basic themes: professional/training and personal experiences. The second organising theme was “Attitudes”, which had the following basic themes associated with it: towards patients, towards treatment and towards the healthcare system. The third organising theme was “Patient care” and its associated basic themes were existing medical care, other support, outcomes for patients, outcomes for the healthcare system, barriers to care and future of care. The global theme of individuality will be discussed later in the chapter.

Table 5.2 – Themes from the HCP participant group data

Global theme	Organising themes	Basic themes
Individuality	Working experience	Professional/training
		Personal experiences
	Attitudes	Towards patients
		Towards treatment
		Towards the healthcare system
	Patient care	Existing medical care
		Other support
		Outcomes for patients
		Outcomes for the healthcare system
		Barriers to care
		Future of care

5.2.1. Working experience

A large part of the data obtained from interviews with healthcare professionals involved their experiences of training and carrying out their day-to-day activities within their working environment. This emerged as an important theme in their overall experience of healthcare delivery.

5.2.1.1. Professional/training

The healthcare professionals' experiences of their education and training, both in their initial undergraduate training and in terms of continuing professional development (CPD), varied considerably both within professions and between professions. Pauline explained that she had no specific training in respiratory nursing when she started to work as a nurse with COPD patients. She did not appear to think this was unusual but explained that she needed a lot of support in the first year and referred to it being 'hit and miss' at times. Pauline remembered, *"...probably the first year I had no training at all...anything that related to respiratory patients,"* (48) and *"...because there's been many a time in the last twelve months when I've not been able to do something and I've had to ring the respiratory and say 'Will you come up and show me, I don't know how this works?'"* (89). However, despite some misgivings, it was clear from the interview that this form of in service training had provided Pauline with a good foundation for later work with respiratory patients.

Tom also found that, as a respiratory physiotherapist, he was in the situation of working at times in the field of palliative care, for which he had no specialist training. However, the experience of Tom differed in that this was a situation in which he was trying to fulfil a specific need, which arose as one part of his role, and it therefore did not affect a large part of his day-to-day work. Tom explained, *"We do have people on our, kind of palliative list...we'll go and see them a minimum of once every two weeks normally...and try and manage them like that. But, as I say, it's ad hoc, amongst all of our other things. It's not something we're specifically trained in"* (556). Both Pauline and Tom had received training as a healthcare professional but had found themselves to be acting in a specialist role, which had necessitated further training.

Naomi talked about the ongoing respiratory training that she had experienced as being an important part of her professional development. She talked about the postgraduate training that was available to nurses working in primary care in their area, *"...regular respiratory meetings...for...staff from general practice. There are regular meetings for practice nurses...I know it's several times a year with different speakers, different topics, so, erm, it's really good to, you know, raise awareness in general practice"* (202).

Tom did feel that, in general, professional training for those wanting to work with people with COPD had improved over the last ten years. Speaking from his own experience, he felt that both training and awareness of the condition had increased in recent years. Tom said, *"I think, certainly, from the last ten years, there's been much more increased focus on COPD. Not just within the health service but also within training"* (434) and *"...health service staff are more aware of it. I think GPs are more aware of it now"* (439). He indicated that he felt there had been an increased focus on COPD in both undergraduate and postgraduate training for healthcare professionals and other workers within the healthcare system.

Linda spoke about the disillusionment she felt during her early years of training and then working as a nurse. She spoke passionately about her belief in a holistic approach to patient care and how she failed to find this in general nursing or psychiatric nursing. Even once working in psychological services, she explained, there was still a problem, in her opinion, with the healthcare professionals' understanding of medication. Linda's frustration with the present healthcare system was evident throughout the interview and could be traced back to their account of those early years of her career as a healthcare professional. Linda spoke of going in to nursing hoping to care for the patients in a holistic way but then finding their experiences very different from what they were anticipating, *"...when I went into general nursing, I found that peoples'...psychological or their emotional needs were not met at all"* (401). She continued, *"...but when I went to work in psychiatry, peoples' physical health needs were neglected"* (437) and *"So, I thought, when I go into psychology, everything will be wonderful. Because then we'll be truly holistic...and there's, you know, a missing link about the medication, understanding about the medication"* (470). This account provided an insight into potential differences between distinct professional roles and highlighted the challenges brought about by differing sector attitudes within the health professions.

Talking about the overall care of COPD patients, Simon felt that in the early days of their nursing career, working on the wards in the 1980s, he was unaware of what care, if any, was available for COPD patients in the community. This led him to believe that there was little in the way of social support available for COPD patients

once they were discharged from hospital. He remembered, *“...I was not aware of, you know, what sort of help and assistance these patients got...in the early eighties as regards community care...so I’m suspecting that back in the early eighties, there wasn’t a lot of that kind of help around for those patients”* (168). This healthcare professional felt it was important that COPD patients’ psychosocial needs were being met and spoke about how the concept of patient-focussed care became prominent in the nineteen seventies and eighties. Simon added that those who are training nurses now are very aware of this need to provide psychological support to patients and focus on it as part of the training.

All the healthcare professionals in the study felt they personally offered a good service to patients with COPD. Those who worked in pulmonary rehabilitation (PR) groups were particularly enthusiastic about their work and the benefits the patients get from attending a PR course. Those working in the community spoke proudly of the work they do, particularly in helping people to stay out of hospital and those in primary care spoke highly of the care they provided. For example, James described how the training undergone by the healthcare professionals in his practice ensured that the patients received a good standard of care. He said, *“I think the treatment of COPD in our practice is fantastic actually. They get a superb access to medical staff, they get a, there’s a very robust recall system. Erm, all the nurses are well trained up and well versed in it, and all the doctors are”* (120).

5.2.1.2 Personal experiences

The personal experiences of the healthcare professionals were individual but generally positive and phrases such as *“rewarding”* (Karen, 308 and Tom, 562) and *“look forward to going in”* (Pauline, 579) illustrated this. Several of the healthcare professionals spoke about how much they enjoyed their work and how rewarding it was. They gave different reasons for finding their work so enjoyable but, in the main, the rewards were in seeing the improvements in the quality of life of their patients. For example, Karen stated, *“Pulmonary rehab is the most rewarding job that I’ve had...because the benefits that the patients see are huge...and it’s so simple to do”*

(308). Similarly, Tom said, *"I just find it incredibly rewarding"* (562) and *"It's varied and it's multifaceted and that's what I like about it. Because you feel you can make a difference"* (597).

When talking about their experiences of caring for COPD patients in the hospital setting, Pauline believed that, despite having done her best for the patients whilst under hospital care, there was insufficient support for them out in the community, resulting in frequent readmissions. She explained, *"I look forward to going in...I like working with these types of patients. I like caring for them...I like watching them get better. What I don't like is them coming back"* (579).

Linda talked about working to help alleviate peoples' distress and said she felt this work was 'really important'. She felt that their work was rewarding because it gave the patients time to talk and the resulting emotional release that a number of them experienced was an important part of their therapy. Linda said, *"at least three, maybe four, men that I worked with, who were in tears...and that's the first time they've ever admitted to, or had the opportunity to say they felt useless, they felt a failure...so, I think it was really important to work with people who were feeling like that"* (328).

Simon's early experience of working with COPD patients had a profound effect on his own smoking habit. Having started work on a respiratory ward, Simon described how quickly this had affected him, *"I can remember, I used to smoke before I went into nursing...after doing eight weeks...I gave up...very quickly"* (506) and *"I just thought 'Sod this for a game of soldiers' I actually gave up"* (516).

Ruth's personal experience of the death of a family member played a part in her feelings about the care of COPD patients in Accident and Emergency departments. Ruth explained, *"for an elderly person who's critically unwell...it's a very scary place to be and it's certainly not a nice place to die...you know, my relative died of COPD in A&E...that wasn't the best place for her to die"* (224). This account was a good example of how personal experience affected the working experience of a healthcare professional and how it had contributed to the development of empathy towards the patients.

5.2.2 Attitudes

The attitudes of the HCPs came across strongly in many of their narratives and emerged as an organising theme. Their attitudes towards patients had some common elements but were diverse in other ways while their attitudes towards treatment and the healthcare system were largely positive although they did talk of their frustrations and concerns about the future of care.

5.2.2.1 Attitudes towards patients

Although all the healthcare professionals who took part in the study came across in the interviews as being caring and concerned for the welfare of their patients, they did speak about difficulties and frustrations that arose when patients were not compliant. Their attitudes towards patients depended on the circumstances at the time of their encounter. Frustrations arose in their clinical encounters with patients and these were largely talked about in terms of individuals not following the advice of those healthcare professionals who were trying to suggest ways of alleviating their symptoms.

Karen and Naomi both talked about how they encountered patients who could be helped by changes in lifestyle and increases in physical activity levels but, for different reasons, did not benefit from the advice they were given. These healthcare professionals were both concerned that patients were experiencing muscle wastage through lack of exercise, which comes about when patients become breathless and limit their activity as a way of avoiding attacks of breathlessness. Karen and Naomi were keen to involve such patients in PR groups where they could learn how to exercise in a way that would prevent this deconditioning. Naomi explained, *“They do get this muscle wastage...that’s where...pulmonary rehabilitation comes in. Just encourages them really just to keep going as much as they can even though they’re breathless...try and keep as active as they can really...it’s frightening for them but, you know, that isn’t the right thing to do...because otherwise they do get this deconditioning”* (341).

However, Karen acknowledged that sometimes individuals are not able, or willing, to make these changes. She said, *"...people tend to think 'Oh, I'm breathless, I'm not going to do that'...then it's just a vicious circle really"* (193).

Olive also spoke about patients being unwilling to attend PR sessions and how they had adjusted their lifestyle to avoid breathlessness and therefore felt there was no need to attend. Olive gave the impression that she felt unable to explain the potential benefits of PR to the patients in a way that they would understand and would therefore feel motivated to attend. Olive said, *"I have sent a couple of patients up to pulmonary rehab...but they tend not to want to go...for whatever reason, they're not keen on going"* (139) and *"they never actually think they are breathless...they don't realise because they've adjusted their lifestyle to accommodate the breathlessness"* (234). In contrast, Tom regarded those who are initially hostile to the idea of PR as a challenge and considered it his role to *"prove to these people that it is effective"* (196).

Linda spoke about deconditioning as being initiated by a cognitive situation involving catastrophic misinterpretation of symptoms, which brings about a response in the autonomic nervous system that, in turn, can eventually lead to behaviours such as panic, ringing for an ambulance or being frightened to exercise. In the words of Linda, *"...so they have the autonomic nervous system response that obviously impacts on their breathing, it affects their respiration rate, and it can, paradoxically, make them feel more short of breath...that can bring about a whole host of behaviours, which can sometimes end up with them ringing an ambulance...or feeling they can't cope, or doing a lot less, or not going out...or frightened to exercise...or who have got more and more deconditioned"* (108).

Simon also recognized that COPD is a frightening condition and said that he understood that the patients were likely to be anxious. In addition, Tom recognized the importance of the psychological effects of COPD and talked about how he felt PR could help if patients could be persuaded of its benefits. He explained, *"They don't know how they can control it. They just see this as being this thing which pulls them down, stops them doing what they want to do and therefore I think it significantly alters how they are psychologically"* (146).

However, when Olive talked about the psychological effects of having COPD, it was in terms of it affected the patients' compliance in the respect of medication usage. She said, *"...it's easy to sometimes, to see if they are depressed...because they're not taking their medication, for one, they don't take their inhalers and things like that, so. But not many...are on anti-depressants, if I'm honest, not many"* (101). Olive therefore felt that depression in COPD patients could be recognized by the fact that they were not taking their medication, which, in itself is problematic. She added that their other way of identifying patients who had depression was by looking on their records to see whether they were taking anti-depressants. It would appear unlikely therefore, that this healthcare professional took the opportunity during consultations to screen COPD patients for anxiety and depression or to talk to them about any emotional concerns they might have. It may well be that the nature of the routine COPD review in primary care and the time restrictions make it difficult to introduce factors into the consultation other than those needed to fulfil the requirements of the Quality and Outcomes Framework (QOF).

Non-compliance with medication regimes, patients' apparent misunderstandings about medication and not taking up advice about exercise and lifestyle, was also of concern to other HCPs in the study. Karen said that some patients will not *"take on board"* (319) what the HCPs are saying but made no reference to the need to frame such advice in a way the patient would be capable of understanding. In addition, Karen and Pauline both spoke about patients not knowing how to take their inhalers properly and not understanding their medication but they offered no comment as to why this may be, or what could be done to ensure that patients are better informed when they are first given their medication. Karen remarked, *"Sometimes they're not taking their inhalers and you talk to them about it and they say they will and then they don't"* (323). Pauline added, *"They have no idea...how to take an inhaler"* (242) and *"They just don't understand the drugs and the medication they're taking"* (268). However, these problems or misconceptions concerning medication and exercise are situations that can be addressed at pulmonary rehabilitation sessions, as explained by Mary, *"...they do the exercise and they gradually increase the levels*

and...education...we have talks like on breathing control, inhaler technique, medication” (30).

Linda offered her opinion of why some people do not take responsibility for their own healthcare. They suggested that this was because traditionally, patients have been expected not to do so by the medical profession. Linda also added that the lack of experience of the necessary language required to express their psychological concerns could be a barrier to understanding for some patients. Linda said, *“I think that lots of people don’t take responsibility for their own healthcare because they’ve been trained not to...do that” (290)* and *“...also, their language is not one where they can easily know how to label or identify or talk about their feelings” (306).*

Self-management was a topic that was introduced in different ways. Tom, when talking about patients having “rescue packs” of medication, indicated that sometimes patients will take antibiotics and steroids when it is not appropriate. Tom commented that, *“Patients will always feel better taking antibiotics and steroids...but it may not necessarily be the right thing to do” (346).* However, he did not expand upon whether the patients have a good understanding of what the necessary criteria should be for the use of these medications and, if not, how this could be addressed.

The attitude of the HCPs towards smoking and smoking cessation sometimes suggested that they were not able to comprehend the patients’ situation. Some of the HCPs spoke in a dismissive way about those who were not able to stop smoking and indicated that cessation was largely the responsibility of the patient themselves. Olive simply said *“...you know the ones that will...and you know the ones that won’t” (174)* stop smoking. In a similar way, James said that he gave them the advice and then it was up to them whether they took it or not, *“If they don’t stop smoking, then I don’t lose any sleep over it...that’s fine. You know, I tell them the score and, if they want to do it, that’s fine, if they don’t, that’s fine” (149).* As with the medication, these comments would suggest that, if patients are unable to stop smoking, the blame lies with the patient rather than the HCPs who they come to for support or the healthcare system in which they are working.

Pauline, a lifelong non-smoker, told how she found it difficult to understand the addictive nature of tobacco smoking and to comprehend why people found it difficult to give up. She explained, *"And I've had patients...they can hardly breathe, and they'll take the oxygen cylinder off, and they'll go for a cigarette...and they'll come back, completely cyanosed, on the verge of respiratory collapse...I need my oxygen and I need my inhalers"* (469). Pauline added, *"that desire for nicotine...I don't understand how, when you've already got that disease, probably as a consequence...in some cases of smoking since you were, you know, people say to me 'I've smoked since I was seven', it's nothing to be proud of"* (477). Pauline appeared to be reflecting the attitude of the hospital in which she worked when she said, *"and we get them to sign a disclaimer, that if they collapse or die, while they're out, it's not the hospital's responsibility"* (513). This lack of empathy and the impression given that the healthcare institution bore no responsibility for the welfare of the patient in terms of supporting them with smoking cessation, were indications that the healthcare professionals were probably not meeting the psychosocial needs of their patients in respect of smoking cessation.

In contrast, however, Pauline later described how she empathised with patients when they could not breathe, how she developed relationships with these patients and how emotionally involved she had become when the patients passed away. She said, *"I've probably cried more with COPD patients that have passed away because you develop a relationship with them"* (513). Pauline continued to talk about how rewarding it was when patients appreciated the help she could provide. She said, *"If you can make somebody breathe...they adore you afterwards...it can be something as simple as putting a fan on...and you can see their face change...from sheer horror to 'Oh, thank God, you saved my life'. And it's those types of people you'll never, ever forget"* (542).

A similar illustration of empathy shown by a healthcare professional was apparent in the interview with Ruth when talking about elderly patients being treated in accident and emergency departments. Ruth explained how she understood the patient's fear when faced with the possibility of imminent death. She recounted, *"...you just felt so sorry for them...because, you know, eventually it was going to get them...and was it*

going to be today or not? ...because when you're short of oxygen that's...all you can focus on...is that you're short of oxygen...and you're going to die" (284). This particular healthcare professional talked about doing what they could to care for those in this situation. She explained, "...being with them, talking to them, and trying to provide what you can...if they can have a drink, provide them with a warm...cup of tea...(at) 5 a.m....just trying to get them over the...worst of what they're experiencing at that time" (33).

In another example of empathy, Tom described how the narratives he heard from some of the COPD patients evoked an emotional reaction as he described, *"And, you know, you hear stories from people about what they go through with this and it almost breaks your heart" (486).*

Karen and Tom, both spoke about how they tried to encourage patients by telling them how much can be done to help with their condition. Karen said, *"We often say to our patients 'You're the lucky ones...you're the ones that know you've got COPD, you're on the right medication and you're having the right treatment'" (180). While Tom added, "I always say to patients that being diagnosed with COPD, however upsetting it is, is a good thing...because you had it yesterday and now we know what it is, and you can access services" (453).*

Olive's approach to her COPD patients was somewhat different. Olive believed that the majority of her patients accepted the nursing care she gave them without question. Olive commented, *"They just, if I'm honest, they come in and if they're happy with everything I do, I check the treatment, I can tell them they're ticking along nicely and...they take probably what I say as verbatim" (356). However, she added that there sometimes comes a point where the patient's condition requires the adoption of a firmer approach. She explained, "...if it's at a point where I think they're going to be admitted or they're going to be ill...really ill, or they're going to die, then I think there's a point where it stops, you stop being so nicey-nicey...not frighten them...but I would be truthful...and maybe sometimes a little brutal maybe. But I mean in a nice way...I don't mean in a horrible way because...otherwise they're going to die" (322). She continued, "...sometimes in the NHS you can soften things...you*

soften the truth a little...you just have to pad it out a little bit...to suit the patient. But sometimes you do have to be quite honest” (340).

Olive also described her attitude towards patients in the following way, *“So sometimes I will sit there and see the patient and know where they’re going, and I will say ‘Listen, you won’t know where you’re going, but I know where you’re going...I know what you’ll look like’” (258).* Olive’s descriptions of her consultations suggested that communication between healthcare professional and patient, in this case, was not open and patient centred. The form of communication illustrated by this quotation appears to be a closed statement, leaving no opportunity for discussion with the patient. An alternative approach could be used, where the HCP asks the patient how they feel about their condition and offers them an opportunity to talk about how they see their future. This would open up a discussion in which the HCP could use her own experience and knowledge to advise the patient within the context of the patient’s own experiences and emotional reactions.

5.2.2.2 Attitudes towards treatment

In terms of attitudes towards treatment, the healthcare professionals expressed slightly different views as to whether NHS treatment had changed over recent years. James felt that the introduction of the Quality and Outcomes Framework (QOF) in 2004 had initiated helpful guidelines but that, otherwise, treatment in primary care had remained the same for some time. James explained, *“The care previously was fairly haphazard and one of the things that QOF has done is standardize care and NICE has introduced various guidelines which we’ve generally, over the past few years, tended to follow...so the basis of treatment hasn’t changed very much (over 23 years of work in primary care): antibiotics, steroids and inhalers...bronchodilators have changed a little bit...but otherwise, not really” (20).*

Naomi and Ruth both felt that, thanks to research, medication had improved over recent years and had become easier for patients to use. Naomi said, *“There’s been new inhalers, that we think have made things better, perhaps in the last ten years...I think research, really, you know, has really made things better with medications...for*

respiratory patients...a once a day version was introduced” (286). Ruth agreed, “...techniques of treatment may have changed (in the last ten years) in terms of giving inhalers repeatedly rather than nebulizers” (73).

Simon explained that treatment had improved considerably for seriously ill patients with COPD and that this was largely due to new, less invasive ventilation techniques, such as Continuous Positive Airways Pressure (CPAP) therapy, which supplies a continual flow of mild air pressure to keep the airways open in people who are having difficulty breathing on their own. He said, “ *And I guess the big improvement, certainly at least probably of the last twenty years or so, has been with, er, the involvement of CPAP therapies...our ability to care for these patients has been improved...through these technological advances...because it means you don’t need to flatten the patient with sedative type drugs*” (50). Simon continued, “*So...from a critical care perspective, there’s been a lot of change...it was often the case that if patients were brought in who clearly had an exacerbation of their COPD...it would have been that their management would be very, very difficult, because in those days, we did not have the technology or sophistication that we have (now)...our ability to care for these patients has improved*” (43).

Tom and Linda both felt there was a need for a more holistic approach to the care of COPD patients, how it is necessary to take into consideration the ways in which the individuals in their care live their day-to-day lives and the psychosocial influences that act upon them. Linda challenged the medical model of care and the ability of GPs to manage the care of people with long-term conditions. She talked about how she had been involved in a trial, which had enabled her to work within a biopsychosocial model and how this had reinforced her belief in the future of this type of care. Linda explained, “*I’ve always believed in a holistic approach to care. I think the biomedical model doesn’t often serve people with long-term conditions...I try and use a much more biopsychosocial approach to people’s healthcare*” (13). She continued “*So, for me, to be able to...address much more of how that individual was, and their narrative and their story...and their background from every sort of perspective...not just the biopsychosocial, but every other aspect relating to, you know, the wider circle than that...and then to give them proper care that’s going to*

make a difference rather than lots of people getting involved giving bits of care...and still not addressing the situation or the problem...I am now feeling more hopeful” (478).

Tom also took into account the individual needs of their patients and described how treatment for COPD patients needed to be flexible. He said, *“I think you have to be sort of pragmatic with COPD...because it’s a variable condition and everyone varies from one to another...and have an open mind on it...their lives are very different from one day to another, so I think you have to adapt” (615).*

In contrast however, James, felt that the traditional primary care setting in which he worked provided good medical care for the COPD patients referring to it as *“fantastic” (120).*

5.2.2.3 Attitudes towards the healthcare system

This theme of attitudes towards the healthcare system was one where, again, individual experiences led to some variation in what the interviewees considered to be important. However, there was a certain amount of agreement across the disciplines concerning the apparent low level of priority given to the treatment of COPD in the healthcare system, in terms of awareness of the condition and financial input.

Karen and Tom both referred to COPD as being seen to be ‘unglamorous’ and therefore not regarded as a priority in the healthcare system. Karen said, *“...we’re just a small pebble in a very big pool..... They’ll do anything for heart disease but, for the poor old smokers...who are struggling...it hasn’t just got that glamour touch, I think...coughing up phlegm is not...glamorous is it, no....” (446).* Tom agreed, *“For some reason, things like heart disease and cancer (are given more consideration)”(463) and “...I think it’s (COPD) seen as being a little bit unglamorous in that it’s phlegmy, it’s coughy, it’s wheezy, it’s breathless. But it’s a huge problem” (467).*

Simon also compared the attitudes of the public and the healthcare system towards the treatment of COPD with their attitudes towards other services. He stated, *"...the sort of big bang services like heart surgery...and that sort of thing, or brain surgery...or whatever. They grab people's attention...(they) want to make sure the money's available for that"* (442).

Financial constraints in the NHS were considered to be an important concern for some of the interviewees. Linda, talked about psychological therapies for people with long-term conditions and how they believed they could have an important impact on keeping people out of hospital and therefore reducing costs to the healthcare system. She said, *"...people with COPD...are also three times more likely to suffer from...generalised anxiety disorder...and the prevalence rate for panic disorder is ten times higher...in the COPD population...up to now, it hasn't been recognized, it hasn't been assessed, it hasn't been treated..."* (84). Talking about the financial implications she added, *"...there's so much money spent unnecessarily on, you know, even just being in, it's over £500 to have somebody as an in-patient for one night"* (616).

In addition, Tom talked about how interventions that help to reduce hospital admissions, such as PR, could contribute to both a reduction in health costs and an improvement in patients' quality of life. According to Tom, *"The cost of COPD in the year is well over a billion pound...and most of it through acute admissions. So obviously, now it's being seen as important to try and limit that. Not just for healthcare costs but for patients' quality of life as well"* (252).

Despite the financial constraints that the healthcare professionals talked about, there were several examples given of their experiences of good patient care. Simon spoke about the need to prioritise patients' needs and preferences and how this is being brought about. He explained, *"...I'm sure all, ...patients would...vastly prefer...to be treated in their own homes.... You know, people don't particularly want to go to some anonymous, enormous hospital...and meet people they don't know, they don't know where they are, and they've had to travel miles to get there etc...certainly people are more aware that they might be able to get community assistance"* (326).

Tom gave a description of how PR works and how it makes an important contribution in supporting the psychosocial needs of the patients and reducing the need for hospital admissions. He described it as follows, *"I personally see rehabilitation as being a little like the fire triangle, where you have, you know, heat, fuel and oxygen...you take one away and the fire doesn't exist. I quite firmly believe the same is true with rehabilitation, like you have the exercise, you have the education and you have the social cohesion as well and actually learning that you are not the only person living with this...and a bit of support, and I think all three come together with rehabilitation"* (125).

However, although examples of good practice were given, there were some criticisms of the healthcare system. Linda, in particular, felt that there were problems with the origins of the healthcare system. She explained her view, *"So medicine split the mind...you know, it's like the church took the soul and it allowed medicine to have the body then medicine fought amongst itself for the body...so it became you know, different sort of...specialities and body parts and they took the brain and split it twice, you know, half to psychology and half to psychiatry. And ne'er the twain shall meet"* (501). She continued by explaining that she felt that the present system of care for those with long-term conditions and comorbid psychological problems was not working adequately. Linda expressed their views with conviction, *"at the moment, what is the doctor able to offer anyone for long-term conditions? And what are they able to offer anyone with long-term conditions and panic disorder or depression, or anxiety...or specific phobias, or PTSD, or OCD, or any of the other conditions that they might have? What are they able to offer? Pills? Do the pills always work...what else is there?"* (538).

Furthermore, Linda said that, in her opinion, she perceived a conflict of interest existing in the healthcare system, which is making it difficult for psychological therapies to be accepted as beneficial interventions for COPD patients. She added *"...whole set up is based around being able to do certain things with very, very powerful bodies and very, very powerful pharmaceutical interests, neither can survive without the other...."* (568)

Tom, on the other hand, saw a lack of awareness of COPD and under diagnosis of COPD as being the main problems in the healthcare system at the present time. He explained, *"I think COPD should be talked about a lot more. I have...people I talk to who work in medicine who don't really know what it is"* (480) and *"...unless we're diagnosing all these people, how do we get them on inhalers, how do we get them aware of the need to stop smoking? How do we get them into rehab, show them how to exercise, give them those tips, techniques?"* (448). Tom continued by stressing the importance of the work done in PR groups and how he felt that it was not being recognized as such when compared with acute care. Tom explained, *"...the rehabilitation side of things is sadly still seen as being...kind of the poor cousin of the service...because...when we're doing our acute supported discharges and admission avoidances, you can...say how much that's saving the NHS...in terms of bed days, or ...GP contacts, or A&E admissions. Whereas rehabilitation's...a lot longer picture really"* (86).

All the healthcare professionals in the study held strong, although widely differing views on the healthcare system as it exists at present.

5.2.3 Patient Care

The theme of patient care dominated the majority of the interviews with HCPs. They spoke in detail about their contributions to the care of patients at the present time, other means of support for patients, the outcomes, barriers and their hopes for the future of patient care.

5.2.3.1 Existing medical care

In the UK healthcare system, care for people with COPD comes from a number of sources; for this study, representatives of the different roles involved in this care were taken from the following groups: general practitioners, practice nurses, nurses and former nurses with respiratory experience from secondary care, respiratory physiotherapists, nurse practitioners, nursing academics and psychological

therapists. At the time of data collection, these participants were working, or had experience of working, in The NHS in North-West England in the following sectors: primary care, secondary care, PR groups and community respiratory services. The data obtained from these interviews with healthcare professionals in different disciplines contributed to a fuller picture of the overall experience of care for people with COPD.

Naomi and Olive spoke about how they carried out the majority of routine care for their COPD patients in a primary care setting. Olive, for example talked about being the main source of care for COPD patients in the practice. She explained, *"I come into contact with COPD patients on a regular basis, every day. I see patients for monitoring of their treatment...patients that the GPs are querying whether they have got COPD, and we do a screening for COPD"* (6) and *"I actually see all the COPD patients at home as well, when they become housebound"* (183). Olive also said that there was good communication between the GPs and practice nurses in the practice, which enabled them to divide the care of their COPD patients in a way that would make best use of their particular skills and experience.

In a similar way, James said that his GP practice also managed the care of their COPD patients in the majority of cases and only referred them to secondary care if they had additional medical requirements. He explained, *"...we hardly send any to hospital at all, unless they've got pneumonia...and we have none, hardly any, under the outpatient clinic unless they've got other complications like...pulmonary aspergillosis...or heart failure...the nurse does the general reviews and the doctors tend to treat the acute illness"* (55).

Olive also spoke about becoming involved in a new initiative in primary care that was coming into practice over the next few months and is designed to help the COPD patient, or their carers, to identify and treat potential problems in the early stages and thus reduce hospital admissions. This particular scheme involves input from the practice nurse but Tom described how COPD teams working in the community carry out similar work. Tom talked about the scheme, which aims to treat people in their own homes following an early discharge from hospital in order to manage patients' care at home and reduce the number of repeat admissions to hospital. This scheme

was a part of the work of the community COPD nursing team whose work also included advising patients when to take their emergency medication packs, running community clinics for respiratory disease and PR groups. Tom explained, *“we run a hospital from home service for them, seeing them for between three days and sometimes two or three weeks...managing their symptoms...anyone who comes into hospital...who has an uncomplicated exacerbation of COPD, we...try to get people out of hospital quicker”* (227).

However, Tom was ambivalent in his feelings about the use of “rescue packs” of medication for patients to keep at home in case of an exacerbation of COPD, *“what we try and advise though, is that they still contact us before taking them because, obviously, a lot of the time, patients think they’ve got a chest infection when they’ve only got a simple exacerbation and they think they need to take steroids when all they need to do is take the day off and put their feet up a little bit...the problem of antibiotic over-prescription”* (337).

If, however, patients did need to be admitted to hospital, Pauline explained that there was a comprehensive package of care, covering a range of psychosocial as well as physical needs, available in the hospital where she had been working. She described how, *“Everybody’s assigned a social worker”* (332), *“...they all have input from a physio* (335), *“...they all have referral to occupational therapy”* (341) and *“...they all have speech and language referral”* (344). Although Pauline felt that this constituted a good overall package of care, it would appear that the patient would be seeing several different HCPs rather than be cared for by one person, or team, who could coordinate all aspects of their care.

Olive added that communication between primary and secondary care was also very good, which enabled her to follow up patients who had been in hospital, using the information sent from the consultant. She explained how this ensured good continuity of care, *“...if, for whatever reason, they have to go (to hospital)...the GPs always send me a copy of the discharge letter...”* (88).

Pulmonary rehabilitation (PR) is an intervention available to some COPD patients that combines a programme of exercise with health education, including breathing

control and social support. Karen and Tom, in particular, spoke enthusiastically about the work of PR groups and how beneficial they are for the patients in supporting them to manage their condition.

Karen outlined the main benefits offered by PR. She explained, *"We will then get the patient into clinic...and we would check that all their medication is optimised"* (59), *"Because they're breathless, they're not doing as much activity as usual...they're not using their legs...and their postural muscles as much, so we try to strengthen those up and it's hugely beneficial"* (91).

As Tom explained, an important part of PR is learning techniques to control breathing and handle breathlessness. He described how, *"...what we're trying to do with patients is to me, really say, you know you've got this condition, yes, it's probably never going to go away, but in terms of there's nothing we can do about it, well, there's actually quite a lot you can do about it"* (137) and *"We also do talks on breathlessness, ways of managing breathlessness: pacing, positioning, breathing techniques, that sort of thing"* (293). Tom spoke enthusiastically about how PR is designed to be enjoyable and supportive as well as educational. He said, *"...we have music, we try and be quite outgoing with patients. It tends to be quite a sort of cohesive environment, er, the education as well, you know. I think people learn a lot from that as well"* (121).

Karen and Tom both said that people seemed to enjoy their time at PR and that they, as health professionals found it was a rewarding area to work in. However, PR does require collaboration with the patient both during the course and as follow-up, for full benefit to be obtained. Participants are provided with individually designed exercise programmes, which they carry out under supervision at the group meetings, usually twice a week for eight weeks. In addition, they are asked to exercise, according to the guidelines they are given at PR, at home between sessions. As Tom explained, *"The guidance is generally, people should be doing exercise three, more likely, four times a week and obviously we only run the sessions twice...suggest they start doing stuff at home as well. What we also have is once they've finished, we refer them to the continued exercise group that's run through the council"* (158). As described by Tom, once the PR course has finished, continuing support is available

for patients who can attend exercise groups in local gyms at reduced rates. Karen explained that there are other options that those who complete a course of PR are able to access, such as Tai Chi or Pilates.

Not all patients, however are able, or willing, to attend a PR course. For some, this may be because there are no courses within a suitable distance from their home and for others; it may be that they have not been informed of the potential benefits. Naomi said that patients in her practice rarely went to PR although, in her experience, those who do go benefit from it. It was unclear why the patients in this particular practice did not attend although; it is possible that, if the person who is referring is not confident of its benefits, this will be passed on to the patients who will then be less likely to be motivated. Similarly, James said that patients from the practice in which he worked preferred to attend local gyms to keep fit and only a couple of them had attended PR courses. He added that those who had attended PR found it very good but that their patients preferred to use local gyms. Again, the reason for this was not given.

In addition, Mary spoke about how PR helped the psychosocial needs of those who attended. She referred to the close contact of the PR group with a Cognitive Behavioural Therapy (CBT) practitioner who comes to talk to them and will assess patients who feel they may benefit from psychological therapy. PR is an intervention in which the psychosocial needs of COPD patients are taken into consideration as an integral part of the course. Mary, when asked if they thought that PR dealt with the psychosocial needs of COPD patients as well as their physical needs replied, *"Definitely"* (66). Mary expanded on this by talking about how the PR course in which she had worked, had talks from a CBT practitioner and how people are able to follow this up if they thought it might be helpful to them.

In general practice, Naomi reported that they did screen patients for depression with two questions and checked if they were on medication for depression or anxiety. They explained, *"Erm, we do depression questions...it's just the basic two questions...we always ask about depression, not particularly about anxiety. I mean obviously you can see what medicines patients are on, if they are on antidepressants...or anything for anxiety, you can see that"* (101). However, Naomi

did not expand upon what steps would be taken if these psychological conditions were identified.

In a similar way, James said that COPD patients in the GP practice where he worked were screened for anxiety and depression. However, he added that there was very little access to psychological services in their particular area. When discussing the provision of psychological therapies for people with COPD and comorbid anxiety or depression, James explained that it was sometimes necessary for GPs to prescribe medication to treat these patients, as *"...the problem with the local system is that it's so poorly resourced that the waiting lists are phenomenally long and therefore making them fairly useless"* (69) and *"...provision of psychological therapies is pretty thin...tend to give them antidepressants instead"* (73). James continued by explaining that he felt this lack of resources had several causes, *"...it's financial, training, political priorities"* (79) and *"It's with psychological services as a whole...I suspect it's...under-resourcing generally"* (91).

Olive talked about being easily accessible to the patients by telephone in times of distress and said that she gave them strategies to help them to cope with their anxiety. She said that, if patients became anxious, they could telephone the surgery to speak to Olive directly. She explained that, *"They manage to be OK"* (115) and *"...they know what to do if they do get anxious...I write a little plan out...and they can ring me any time if I'm in... if they're panicking...it's easier to speak to them on the phone...than try and get them in"* (124). Unfortunately, Olive added that she did not work every day in the week and therefore this one to one support was not available at all times. In terms of psychological support for patients who had been admitted to Accident and Emergency departments with an acute exacerbation of COPD, Ruth said that, there would be no screening for anxiety and depression when a COPD patient was admitted, although they would be assessed on the ward.

With reference to whether the present healthcare system meets the psychosocial needs of COPD patients, Simon talked about the concept of holistic care and how it was something that is now an important part of nursing training at undergraduate level. Simon talked further about this aspect of nurse training, *"...those holistic perspectives...including, sort of, the psychological side of it and how do you help*

support people...from that perspective. You know, so people don't perhaps erm, feel alone, abandoned etc. and of course that just leads to create other problems such as anxiety and depression ... it's something that...try to focus on (in training)" (370).

5.2.3.2 Other support (family, friends, support groups)

In addition to the provision of care by the healthcare system, people with a progressive illness such as COPD will increasingly need support from other agencies in order to carry out their activities of daily living. Ruth talked, from her own experience, about the lack of support for patients who were admitted to A&E with a crisis during the night when family and friends may not be able to be there for them. In addition, Ruth emphasised the need to ensure that support was in place before a patient was discharged home from hospital. She explained, *"I mean you'd have to think seriously about whether you felt your patient would be safe...to send home, if they had no support in place, because...they would be a repeat attender...so whether they've got, they've already got home care set up or they've got district nurse support, you know, that would make a big difference on whether you were going to send them home"* (98).

Some of the HCPs spoke about their patients' need for support from family and friends. Pauline was concerned that the care people receive in the community was not adequate. She emphasised that a care worker may have only fifteen minutes to attend to a patient in their home and that COPD patients are often unable to get up and dressed in that time. Pauline described the difficulties, *"...they (carers) get ten, fifteen minutes, twenty minutes maximum time with them. You try and get a patient out of bed with this condition in twenty minutes...because they can't breathe, they have to take their time...it can take two hours...they haven't got that in the community"* (617). Consequently, it is often the patients' relatives or friends who provide the support they need. The support given by the family may be as straightforward as checking that the patient takes their medication according to their care plan, it might be helping with housework or shopping or, in a crisis, family members may be the ones who ring for a GP visit or an emergency ambulance.

Family support was considered important by Pauline who said that they felt that those who were admitted to hospital and had a good family support network were more likely to have a better outcome. In the event of an emergency admission, Pauline talked at length about how they believed a lack of family support in some COPD patients, manifested itself in that situation. Pauline explained *"The ones that have got bruises all over them...and have no teeth in, or have brought a set of false teeth that are black. You know there isn't a family...connected to that patient"* (299). On the other hand, Pauline felt that those who did have family support were more likely to experience a good outcome. She added, *"and the ones that are well-dressed and the chiropodist has been to their toenails...they come in with a bag of toiletries...and a bar of soap, and a towel and clean pyjamas or nightie, they are the better looked after...they do better because they have more to live for"* (307). They added that the positive effects of family support continues once the patient is out of hospital. Pauline expanded upon this by explaining that those who had a partner to care for them or family members living nearby had better outcomes than those who had no support on a regular basis.

In addition to the emotional and practical support provided by family members, people with COPD also benefit from the support of friends and social groups. The social support of a PR group was something that Karen felt was important and said that many people find it helpful to feel that they have the support of others. Along with the exercise and educational aspects of a PR course, the social aspect of PR was something that Karen emphasised in her interview as providing a source of support to patients. She explained that those who are unable to attend PR, *"...they don't have the benefits of being in a social group...they don't have the support of each other, which a lot of people find very, very helpful on the pulmonary rehab programme...they realise they're not on their own"* (271).

In the voluntary sector, Breathe Easy is a network of support groups, affiliated to the British Lung Foundation, for people with respiratory illness. However, healthcare professionals may not be aware of how to put their patients in touch with their local group. For example James, working in primary care, was unaware of the existence of the group. He commented, *"...are there any?...I thought I was their support group"*

(98) and *"...don't know anything about it...actually I'd be interested to hear more about that"* (111).

Although the Breathe Easy support groups were not necessarily familiar to those HCP participants in the study who worked in primary care, the PR groups did have people to come and talk about them and encouraged the patients to attend meetings. Tom was aware of the need to publicise Breathe Easy to the people attending the PR courses. He explained, *"Breathe Easy is incredibly important...it's social, people who have COPD who feel that no one understands about it and...it's somewhere for them to go and people really enjoy it...the group had been quite a big success really"* (275). As a result of attending a PR course, one of the members of patients had seen a need for more self-help groups in their area and, with the support of one of the respiratory nurses from PR, had started a new branch of Breathe Easy.

5.2.3.3 Outcomes for patients

The outcomes for COPD patients, both physically and psychologically have, according to the healthcare professional in the study, improved over recent years. Different healthcare professionals talked of improvement in various areas, according to their individual disciplines. For example, in primary care, James said that more awareness of and help with smoking cessation was an important contribution to good outcomes whereas Olive said that diagnosis and starting patients on medication made them *"feel like a million dollars"* (246) .

In terms of secondary care, improvements in outcomes for patients were talked about in terms of greater awareness by medical professionals, better treatments and therapies, and improved organisation in hospital care. For example, Ruth recalled the death of a relative in A&E some years ago as a distressing outcome but also contrasted this incident with the experience of another patient who had passed away in hospital with COPD recently, and had received a better standard of care. Ruth said that, in comparison to their relative's experience, *"I felt she had as dignified death as she could"* (85).

Pauline agreed that the care of COPD patients in hospital now had improved since she did her training in the nineteen seventies when there was little the doctors could do for the seriously ill patients and many of them did not survive. She explained, *"The care delivery that's given by the doctors is more proactive now"* (383). Pauline added that improvements in hospital care led to fewer deaths from COPD and more opportunities to lead a relatively normal life at the later stages of the disease. She explained, *"...they tend to pass away with (something else)...not so much now with COPD"* (394) and *"...you can lead a reasonably normal life...not do a lot of the activities that you probably did in your twenties but there is still life to be led there"* (449).

With regards to hospital inpatient care, Simon agreed that outcomes have improved although they put more emphasis on improvements in treatments and therapies. He said, *"the treatments and therapies are vastly improved, the diagnosis has improved and our ability to treat them all the way through"* (78). The healthcare professionals were in agreement that outcomes for COPD patients had improved, and their particular disciplines came out as being important factors when talking about how these better outcomes had come about

Those who worked in PR said that it had a positive effect on physical outcomes, psychological outcomes and quality of life, all of which were apparent in assessments before and after completion of the course. Karen explained, *"(they) come in and do a six-minute walk test around some cones...and they fill in a series of questionnaires...also we do Hospital Anxiety and Depression scores as well...so that we can assess how well they've done"* (65).

The physical outcomes are probably the most readily apparent as in Karen's example of a lady who benefitted from three consecutive courses of PR. She described how, *"...we had a lady who came who had been in hospital, had been sent home and she couldn't walk...she did three programmes back to back, one after the other, because I felt I hadn't got out of her, her full potential. And, by the end of the programme, she was able to walk quite a distance...a massive improvement for her...she could manage the stairs and things like that"* (333).

All the HCPs expressed the view that physiological outcomes for patients were improving, in addition, those working in PR spoke about their part in improving psychological outcomes. Most of the HCPs were aware of the importance of treating the whole person and not simply the disease. Karen talked about how patients were assessed both physically and emotionally, before and after a course of PR and, in terms of meeting the psychosocial needs of the patients, Tom added that, after completing a course of PR, patients had, *"Significant improvements in quality of life scores and Hospital Anxiety and Depression scores"* (120). Tom explained that, although the team they worked in had not been trained in psychological therapies, helping the COPD patients to improve their quality of life and improve their scores on anxiety and depression scales, was an integral part of their care. Tom expanded on this by saying, *"We're not trained psychologists but, you know, we get our outcome measures on HADS scores"* (148).

Mary also talked about how patients are assessed after a course of PR and how this information is communicated back to their GP. She said, *"...at the end of eight weeks they come back to us to be reassessed in the same way that they were at first. Then whoever referred them and their GP gets a summary of how they've done"* (35) *"I would say that everybody benefits from pulmonary rehab"* (40). They also discussed the apparent benefits of PR even for those who are initially unsure about taking part. According to Mary, patients who are apprehensive about whether the course will be able to help them, come out feeling pleasantly surprised at how much better they feel, from both a physiological and psychological point of view. Mary explained, *"...patients surprise themselves...because a lot of them are very apprehensive at first like 'How can this help me? I'm very breathless, I can't do this, I can't do that'...and then they come out of it feeling very different...physically and emotionally"* (42).

Naomi agreed that patients did benefit from the wide range of topics covered in a course of PR. She described how, *"...as well as the exercise programme and it's quite a nice informal atmosphere, so they get...education about diet, breathing and anxiety, breathing techniques...I think it's really good"* (137). On the other hand, Olive said that she rarely referred patients on to PR from their GP practice although, when she did feel it was necessary, the patient did benefit from the intervention.

Tom continued to talk about the positive outcomes for patients who attended PR courses although there were some in his experience who had initially needed a little persuasion. He recounted how important it was to help the patients to understand the potential benefits of PR when they are initially referred, as some are not receptive to the idea at the outset. Tom gave one example, *"...a gentleman who came in on Friday, who was hostile as anything. He spent five minutes ranting and raving at me about...all about aspects of his treatment...he wasn't happy about his medical management and he thought it was a complete waste of time. He didn't see why he was there, he didn't see the purpose in it, by the end, I think I'd talked him round as to why it was effective"* (203).

Linda described how, in her experience, psychological therapy had achieved good outcomes for some COPD patients who had comorbid anxiety and/or depression. Linda talked of working in a patient-centred way, in which she discussed with the patient what they wanted to achieve from their treatment, and tailored the therapy to suit the individual. This approach, according to Linda, produced good outcomes in all areas of the patients' lives. She explained, *"...it would just be kind of really looking at their lived experience and what they wanted to achieve and the steps to help them to do that and to get their life back...there's the spin-off socially as well"* (229).

Linda recounted various examples of the different positive outcomes that COPD patients had experienced through psychological therapies. For example, she talked about how one particular patient had achieved their desired outcome of resuming her social life and how it had affected the patient's husband as well. She recounted, *"I had a lady and she was...frightened to go out, because one day she went out and she had a particularly bad attack...she thought she was going to die and she ended up a virtual prisoner...and, at the end of her treatment, her husband said to me 'You've given me my wife back'"* (145). Linda felt that the kind of treatment these patients had undergone, an individually adapted course of CBT, had produced improvements in several different areas of life, physical as well as emotional. In the words of Linda, *"...big improvements on all life areas...improvements in mental health...but what was more surprising was that we also used a lot of physical*

measures...like the CAT and the BORG and also quality of life questionnaires...and what we found was that there were improvements across the board” (179). Other successful outcomes were described by Linda, including people who managed to reduce their medication use, a patient who stopped smoking and became re-employed after several months and a lady who had been able to take up driving again.

Linda continued by giving her views concerning the satisfaction of patients who had undergone psychological therapy when compared with the reactions of those who relied only on traditional medical treatment for their psychological conditions. In Linda’s opinion, *“I think that lots of people go to the doctors and feel upset or disappointed or don’t feel they’ve had their needs met because they just end up with another prescription for pain killers that are no longer working or antidepressants that aren’t stopping them feeling depressed, or continuing to have panic attacks because there isn’t any medication for panic attacks” (559).* In addition, Linda said that they had experienced higher levels of patient satisfaction through psychological therapy as opposed to medication alone.

Again, there was a certain amount of agreement amongst healthcare professionals in that they felt the outcomes for COPD patients were improving. However, there were individual differences in the views regarding how this is being achieved and these differences were not entirely accounted for by the differences in disciplines.

5.2.3.4 Outcomes for the healthcare service

In addition to improving patients’ quality of life, HCPs were also aware of the financial benefits of PR to the healthcare system in reducing the number of hospital admissions. Karen and Tom agreed that attendance at courses of PR is bringing about a reduction in hospital admissions and this, in turn, is improving patients’ quality of life as well as reducing costs to the NHS. Karen expanded on this by saying, *“I think that people are becoming more and more aware of the benefits of pulmonary rehab...and how it’s actually stopping admissions...and the admissions that do occur are shorter...there’s a lot of evidence around that” (434).*

Views on outcomes for the healthcare service did depend upon the particular discipline of the healthcare professional to some extent, but there are some commonalities. Tom, Karen and Linda all talked about how PR and psychological therapy decreased costs to the NHS by reducing the numbers of hospital admissions. Tom referred to the work of the community COPD service, *"...admissions for COPD, since the COPD service started in 2009...I think are down by about...thirty-five to forty percent...for acute admission. If you start working that out at a minimum five grand for an A&E admission and a night's stay...it speaks for itself really"* (492).

Linda made a similar argument for the use of psychological treatments, *"I think you could, you could save a fortune...there's so much money spent unnecessarily on, you know, even just being in [hospital]...if you have this treatment it pays for itself, over and over and over again...so you could save huge amounts of money"* (614).

Ruth stressed the importance of health education in illness prevention, such as that promoted in PR groups. She explained, *"...illness prevention is important with every illness isn't it?...if there's education to be had, then that's always going to improve outcomes"* (255).

As far as primary care is concerned, Karen said that an increasing awareness of the work of PR amongst GPs has led to an increase in referrals from them to the service. This increase in awareness amongst GPs could be partly due to good communications between the PR teams and primary care teams, as described by Mary earlier. If GPs are made aware of good outcomes from sending patients to PR it may lead to an increase in referrals.

Also in the primary care setting, one outcome of the practice nurse taking on more responsibility for the routine care of COPD patients was described by Olive. She explained that, if the nurse is trained to carry out routine care of COPD patients, the GPs are then available to treat acute illnesses.

Unfortunately, however, Tom felt that the good outcomes from PR were not fully appreciated by those in authority. He stated, *"...we do get quite a good output through it but, you know, I still see it as being something which often is the patients and the staff here see the value a lot more than maybe, you know, sort of, higher,*

higher powers” (104). This apparent lack of awareness of the value of interventions such as PR and psychological therapies, in the view of some healthcare professionals working in the field of respiratory disease, may lead to barriers to the care of COPD patients.

5.2.3.5 Barriers to care

Once again, the discipline in which the healthcare professionals were working influenced their perception of the barriers they came across. For example, despite the positive outcomes achieved by PR, and the high level of appreciation by both patients and staff, it was felt by some of the HCPs that it was unappreciated by the healthcare system. Lack of financial resources meant that barriers to care, such as long waiting lists and lack of available courses, caused frustration among some of the HCPs who expressed their desire to help more patients, where and when help was required. This was particularly apparent in terms of PR where one of the main concerns was the long waiting time for a place on the course because of the lack of availability. Karen explained, *“...we’re looking at about five or six months I think at the minute...I’d ideally like to be able to have them into clinic...offer them a place...strike while the iron’s hot...we have a lot of problems with...people not turning up...and I think it’s partly because of the wait...if we could get them when they’re on the boil then...we’d be able to help more people I think”* (233).

Mary and Tom also mentioned the financial restraints of the healthcare service, affecting the availability of PR courses. Lack of funding in general was a source of professional frustration for Karen in, *“not being able to provide the service that I would like to do”* (316). Tom specifically referred to staffing limitations, *“...I think we could comfortably take on three or four staff members more. But, you know, it’s finding the money to do that and the money is still...largely in the acute side of things...whereas actually the chronic management of it...is less valued”* (359).

Transport for patients was something that came up as a barrier to care, and to PR attendance in particular, in the HCP interviews. The practitioners expressed genuine concern for those patients who would benefit from attending a PR course but who

are limited by lack of available transport. Naomi said, *"If they've not got transport...the transport isn't provided so they've got to make their own way there...it's difficult if...they haven't got transport themselves (151).*

Tom talked about one lady who had waited for an hour and a half for public transport to take her home from a PR session and added, *"some of these people are, you know, vulnerable and quite scared...you can entirely understand why they don't want to come back"* (404). He also suggested that the timing of sessions and lack of sufficient information could be barriers to people taking up places on PR courses. Tom expanded upon this problem, *"...because we have set times, we can only get to groups at certain times and some patients say 'Well, I can't do that. I've got to pick my children up at that time...or I'm working, my boss won't give me the time off'"* (395).

Home PR is sometimes suggested as an alternative to group sessions, in order to avoid the problems of transport, but Karen said that this would be difficult in terms of facilities and funding. In addition, those who were able to receive PR at home would not be able to take advantage of the social support that forms a valuable part of the group meetings. Obviously, in the circumstances, ill health was often a barrier to attendance for PR, particularly in the winter months.

Some HCPs, however, saw the attitude of certain patients as a barrier to care. Karen talked about patients who would not listen to what they were telling them and Naomi spoke of occasions where patients might refuse to go to hospital. Karen said, *"...you do get difficulties with patients that...don't listen to what you're saying. They don't take on board what you're saying and you have the feeling that, if they did...we would get a better response from them"* (318). Naomi said, *"...because some people do dig their heels in and say 'Well, I'm not going in...not going in, I hate hospital, I'm not going in, I want to stay at home'"* (94). In both of these cases, there appears to be an assumption that the patient is being uncooperative whereas it may be possible that the situation is not being explained to them in a way they can comprehend. For example, in terms of compliance with medication regimes, Pauline reported, *"...inhalers, they don't know how to take them properly...unbelievable, the number of patients, they can be on three or four and you'll say 'Do you want some help?' 'No, I*

know how to do it' and I'll say 'Show me' and they have no idea...how to take an inhaler" (238).

Similarly, Ruth talked about patients who were unable to give up smoking and some whose illness itself caused mental confusion making it difficult for them to adhere to treatment regimes. With regards to smoking cessation, she said, *"...often it's the case that somebody smoked for years...and they get COPD and frankly...carry on smoking's going to kill them, but they just, it's too hard to give up" (206).* Ruth then described one particularly memorable experience, *"I can recall one specific lady who came in and her SATS were below sixty...SATS at that level leads to massive confusion and she wouldn't...remain for treatment...and we knew that, when she left, she would die...those kind of additional behaviours that come because of the physiological implications...do make it more difficult...to treat the patient" (50).* Again, in these examples, there was no mention of the responsibility of the HCPs to explain the situation to patients in a way that they would be able to understand, in order to help them make an informed decision. However, this may not have been possible in this particular situation.

Naomi, however, indicated that some blame rested with the system in GP practices whereby patients felt they were only allowed a certain amount of inhalers and were therefore not taking sufficient medication when required. She suggested that, *"...they are a bit frightened maybe of taking their Ventolin inhaler too much because the practice says 'Oh, you can only have one'...some of them think 'No, I can't use it, I've got to be really, really bad before I can use this'" (380).* This is a further example of how good communication between healthcare professionals, or practice staff, and patients might be able to alleviate some of the misunderstandings that are leading to problems with care.

Tom also spoke about problems in primary care and from his point of view, under diagnosis and lack of availability of GP appointments were significant barriers to care. He explained, *"...unless we're diagnosing all these people...how do we get them into rehab?" (448).* Tom continued, *"...the general issue with GPs that it's difficult for them to get an appointment" (312) and "...but it's that inability to get a quick appointment at the time you need it" (330).*

However, Linda, when talking about the problems arising with patients, expressed the view that these behaviours have come about because of the attitudes of the medical profession, rather than the patients themselves. She said, *"I think lots of people don't take responsibility for their own healthcare because they've been trained not to...they find it difficult to see that they have a part in it...they have been used to physicalizing their problems"* (290). Linda also spoke about the challenges of treating psychological conditions in COPD patients and the difficulties she perceived with regards to GP training and employee constraints within the NHS. She felt strongly that, *"...if doctors are, continue to be trained in the medical model, how do they have any perception or understanding...the doctor maybe has not had training...in psychological therapies"* (521) and *"I would love to do much more but...as an (NHS) employee, there are lots and lots of constraints"* (606).

For Olive, it was administrative and communication difficulties between different healthcare sectors that caused the problems. She recalled, *"I remember wanting to send somebody up for...an oxygen assessment...it took weeks and weeks and then they kept getting the appointment cancelled...and they never call me back when I've rung..."* (196).

Frustrations caused by the lack of community care, meaning that patients cannot be cared for in their own homes, were apparent in the interviews of some of the HCPs who thought that financial constraints were the reason behind this situation. For Pauline, the lack of adequate community care was an important barrier to good patient care. She recounted her views as follows, *"The care isn't there for people to be looked after in their own home"* (672). Pauline continued to explain, *"there isn't enough focus on continuing care in the community...there isn't enough money there"* (648).

5.2.3.6 Future of care

The healthcare professionals, once again, had individual views in terms of hope for the future care of COPD patients. Despite the frustrations, some of the HCPs maintained a positive outlook for the future of care for this group of people. Some

talked about the need to expand the number of PR courses into more areas and for them to be held at times that are more suitable for patients. Karen said that she would like to run *"satellite groups"* (171) and Mary explained that there were already plans to expand PR by opening another group in the area. Tom said he would like to see PR groups operating in the evenings for patients who work.

Furthermore, Tom spoke enthusiastically about the need to have an integrated COPD service covering all aspects of patient care, both acute and long-term. He said, *"That needs to be available for everyone across the country in every major city...in every area...an integrated service...that covers rehabilitation...the acute service...early discharge"* (487).

Pauline also felt strongly that care of COPD patients in the community should be expanded to provide better care for the patients at home and reduce hospital admissions. She talked about how there is insufficient support to care for people in their own homes and concluded her interview with the following words, *"And it's just immoral, well I consider it immoral. Because the bills would be reduced. If the politicians would just listen, they'd be able to reduce the acute admissions...because we'd look after them in the community"* (672).

Tom was also looking to achieve fewer hospital admissions for COPD patients in the future but had a different, although complementary, approach to that of Pauline. He emphasised the need to equip patients with the skills to manage their own condition and symptoms, *"giving them the skills to have admission avoidance in the future"* (96).

Linda looked forward optimistically to a future where COPD patients would be treated holistically, saying, *"I'm really hopeful and I'm really excited to be a part of feeling that beginnings of a paradigm shift"* (393) and *"I'm just hoping that it's going to sort of open that way so that we're going to be able to treat people instead of a collection of body parts...as a whole person"* (492).

Finally, Ruth posed a question about the future of COPD, *"...it will be interesting to see, you know, where COPD is in fifty years when you know, my generation is elderly and, you know, hopefully we smoke less...and have less pollution...and are more*

aware of health promotion. Where will we be...with relation to COPD, in fifty years?" (295).

5.2.4 HCP group global theme of individuality

As with the COPD group, the HCP group in this study expressed individual views and experiences within the organising themes. Despite working largely with people who have the same condition, their perceptions about patients and their treatment within the present healthcare system were often different. This may be explained in part by their experiences in a particular role in the healthcare system and partly by personal views and experiences.

For example, within those who had worked as hospital nurses there was some variation in the attitudes towards patients. There were expressions of empathy from some and a lack of understanding, particularly where smoking was concerned, from others. In addition, one HCP who said she had trouble understanding the addictive nature of tobacco showed empathy towards patients in other situations, explaining that her own experience of seeing a family member die in hospital had a lasting effect. It would appear that individual attitudes and perceptions held by HCPs understandably informed their approach to care.

Past training and work experience was also highly individual, both between disciplines and within disciplines. There were those who felt that their organised ongoing professional development was effective and supportive whilst others had experience of learning 'on the job', in a more informal manner, in addition to their formal training. One HCP who had experience of working in different fields of nursing expressed dissatisfaction with some of the care she had witnessed but others felt that there was a good overall package of care for patients in hospital.

These individual differences could be perceived as giving a picture of a somewhat disjointed healthcare system. However, the global theme of individuality is not necessarily an indication that the standard of care may be adversely affected by these differences. As patients have individual medical and psychosocial needs, HCPs will

also have their own experiences and attitudes which can be embraced within the healthcare system and contribute to the provision of effective patient care.

The following three chapters of the thesis will further discuss the findings from the two groups of participants; the COPD group and the HCP group. Chapter 6 discusses the reported experience of the participants with COPD and the themes that emerged from their data while Chapter 7 considers the responses of the HCPs. These two chapters maintain the separation between the two groups of participants because, whilst the global theme from each group was one of individuality, the way in which this theme was reached differed considerably between the two groups and there was little consensus in the organising themes from each data set.

The final chapter, Chapter 8, will then draw together the results of the data obtained from the COPD group of participants and that from the HCP group, in order to describe and explain the ways in which these two sets of experiences and perceptions agree and differ in the light of the research question for the study.

CHAPTER 6 – DISCUSSION: COPD GROUP THEMES

This chapter will examine and discuss the organising themes that emerged out of the study data from the COPD group. The themes will now be discussed in terms of their relationship to the literature, the overall theme of “Individuality” and the research question, which was: The lived experience of people with chronic obstructive pulmonary disease (COPD): How are health providers meeting their psychosocial needs?

6.1 Discussion - Lifespan health theme

The first theme to be discussed is that of lifespan health. Many of the participants in the COPD group talked in some detail about their health since childhood and how they perceived that their COPD had developed. This organising theme was related to six basic themes, which were childhood illness, family respiratory illness, exercise, smoking, COPD (its symptoms and exacerbations) and comorbidities. Each of these themes will be discussed individually in terms of their relationship to the literature and to the research question.

Unsurprisingly, smoking featured large in most conversations. Some of the participants in the COPD group talked about being aware that smoking may have caused their COPD, however, childhood respiratory illness, or similar illnesses in other members of the family, were cited by some as incidents that may have triggered their condition later in life (Alison, Elsie, Florence, George). Although I am not aware of any recent literature specifically concerning the perceived relationship between childhood illness and the development of COPD later in life, the findings of this study can be compared to those of Small et al. (2012) who also found that people have their own perceptions concerning the development of chronic respiratory disease and that these perceptions were sometimes the result of social or cultural experiences in their lifetime. In their conclusion, it was stated that there is a need for

local circumstances to be taken into account when dealing with the needs of patients with chronic illnesses (Small et al., 2012). In the present study, the mean age of the COPD participants was approximately seventy years, which means that some were born either before, or during the early days of, the National Health Service (NHS). The availability of healthcare and medication will therefore have changed over their lifetimes. Alison, for example, recalled that she did not see the doctor when she had frequent chest infections as a child and that she was never given antibiotics. The reason for this is unclear as both free GP access and antibiotics would have been available at that time but it may have been that it took some time for people to become used to this availability and to when it was appropriate to seek medical help. Others, such as Elsie and George, said that they perceived that having whooping cough as a baby or young child, contributed to the development of COPD later in life. This illness would have been far more common among young children before the introduction of the preventative vaccine in the early 1950s. Similarly, one participant recalled that her mother had Tuberculosis (TB) when she was a young child before the BCG vaccine to prevent TB, was introduced into the UK in 1955. Whether whooping cough or TB has a direct link to the development of COPD is not within the scope of this discussion, although it is unlikely to have been the trigger for COPD. However, examples such as these indicate the relevance of people's beliefs and perceptions regarding the source of their ill-health.

The work of Bailey et al. (2009) can be related to the data in the COPD group from those who felt that respiratory illness in another family member had potentially played a part in the development of their own respiratory condition. This indicated that some of the participants perceived that the cause of their illness was not entirely due to their own history. When Bailey et al. (2009) explored the narratives of people with COPD, they found a variation in their explanations for the perceived cause of their illness. Some of the participants in Bailey et al.'s (2009) study believed that the cause of their illness was more complex than simply having been a cigarette smoker. This highlights the need for clinicians to consider these individual perceptions of causality, rather than concentrating on the 'fact' that COPD is caused by cigarette

smoking, if they are to provide individualised care for patients with COPD (Bailey et al., 2009). In terms of the global theme of individuality found in this study, the findings of Bailey et al. (2009) are especially relevant, particularly as one of the participants in this study had never been a smoker.

Some participants felt that there could be a family trait that lead to a common tendency towards respiratory conditions. For example, Alison and George had close relatives with similar conditions although George did say that he thought his grandparents' respiratory problems were due to their employment history. This perception can be compared to the findings of Small et al. (2012) above. There was little mention of passive smoking in the interviews but the two who did speak about it held opposing views. Elsie indicated that she doubted the evidence that passive smoking can be harmful but George insisted that, although he had been a light smoker, his health had been affected by the smoke from others in the office where he worked. This difference in perception may be an indication of the individual's locus of control. Elsie appeared to have an internal locus of control in taking responsibility for the development of her COPD through her own smoking history. However, the implication of George's statement was that it was passive smoking, rather than his own light smoking habit that caused his COPD. It would appear, therefore, that he held others responsible for his health status and hence was expressing an external locus of control.

Physical exercise was another theme that emerged from participants' experiences of lifespan health. All of those in the COPD group referred to some reduction in physical ability. Some were aware of the value of exercise and adapted their previous exercise regimes to suit their condition (Bruce, George) whilst others avoided exercise because it caused breathlessness. One of the participants in this study (Florence) spoke about how she would get a lift rather than use the stairs to avoid becoming breathless and another (Harriet) spoke of her breathlessness as a good sign because it tells her when to stop doing physical activity. Exercise avoidance, however, leads to deconditioning and influences COPD outcomes (Bentsen et al., 2010). It has also been shown that anxiety and the fear of exercise-induced breathlessness have a

negative effect on quality of life, functional status and exercise capacity in those with COPD (Janssens et al., 2011). The experience of breathlessness is undoubtedly extremely frightening and perceived as life-threatening. It is therefore unsurprising that individuals feel the need to adjust their lifestyle to avoid this experience. In terms of exercise, therefore, it may be a challenge to HCPs to convince people with COPD that it can improve their physical and mental outcomes. One of the main aims of PR, for example, is to teach exercise regimes that are appropriate for each patient and to provide information and encouragement in order to ensure that people understand the benefits of regular exercise. Evidence that this is taking place came from Bruce who, having attended a course of PR, followed up by going to the gym regularly. However, this particular individual, along with George, had always exercised, understood its value and was happy to continue. There was little evidence from those in the COPD group who had not attended PR that the healthcare professionals they were in contact with had given them any instruction or encouragement concerning the benefits of regular exercise. This may be because GPs, practice nurses or hospital nurses have little time available during which they are able to discuss the benefits of exercise in a thorough and meaningful way. Alternatively, patients may feel that taking up exercise is counterintuitive and therefore distrust the advice they are given or reject it as something they do not wish to pursue.

Again, this theme indicated individual differences between the participants in the COPD group, in terms of their attitude towards exercise, both before and after diagnosis, their awareness of the benefits of exercise and their degree of loss of physical function. As stated above, those who expressed enthusiasm for taking part in exercise tended to be those who said that it was a part of their life before they had COPD and therefore something they felt was of importance to general well-being. Examples of those who talked about slowing down or leading a quiet life were people with other health conditions, such as heart disease or cancer, and therefore may have felt physically less able to take part in exercise or perceived that they needed to take things easier to ensure their recovery from coexisting illness.

An important part of the lifespan health theme was the theme of smoking and its relationship to COPD, in that people spoke about smoking being the cause of their illness, the lack of awareness of its dangers when they began smoking, the challenge of quitting smoking and their perceived attitudes of health professionals towards smokers. Of the participants in the COPD group of the study, one individual (Ian) had never smoked, another (Harriet) did not discuss smoking during the interview and the remainder had stopped smoking prior to the interviews. These findings differed from those of Wilson et al. (2010) who interviewed six participants who, despite being diagnosed with COPD, had continued to smoke. One of the themes from their study concerned the experiences of participants who weighed up the costs and benefits of smoking and subsequently reached the decision that smoking was the only enjoyment they had left in life (Wilson et al., 2010). Furthermore, others felt unable to give up smoking and spoke of being resigned to premature death, and others experienced guilt, diminished self-worth and low self-esteem (Wilson et al., 2010). Although the sample in Wilson et al's (2010) study was chosen specifically as participants who continued to smoke, some of the participants in the present study, despite having attained their goal of smoking cessation, had also experienced similar challenges. Clive initially chose to continue smoking despite being diagnosed with COPD but spoke of his regret at not having given up sooner. Similarly, Elsie said that she had still smoked despite being aware of the potential dangers.

Two participants (David, Elsie) talked of how they were aware of the addictive nature of cigarettes but eventually their deteriorating health meant that they felt they had no option but to stop. This was in contrast to the participants in a study by Jonsdottir and Jonsdottir (2011) who found the addiction to nicotine overwhelming and continued to smoke despite health problems because they felt it relieved the stress of their everyday lives. It would appear that each individual smoker needs to decide for himself or herself whether the risk to health is outweighed by the benefits they gain from smoking. It is therefore the responsibility of the individual as to whether they choose to continue to smoke but I would suggest that it is the responsibility of HCPs to ensure that sufficient relevant information and support is made available to their patients in order for them to reach an informed decision.

The global theme of individuality was readily apparent in the participants' experiences of smoking and smoking cessation. Of those who had given up smoking, each one had a different experience. Most had tried some form of assistance, such as patches or tablets but none said that these had been successful and it had been an individual decision made by each person as to how and when they felt ready to stop. One participant (Elsie) spoke of how she objected to being asked at every consultation whether she had started smoking again. It may be that the HCPs are required to keep an updated record of the patient's smoking status but, in the case of this individual, it was regarded as an intrusion and something that she resented being asked on each occasion. This is an example of how routine reviews may possibly become a place for updating information at the expense of a mutually beneficial relationship between HCP and patient. Nobody in this study spoke about feeling supported by healthcare professionals in terms of smoking cessation. Therefore, in terms of the research question, support for smoking cessation could be regarded as an unmet psychosocial need. However, accounts from participants of having been given pharmaceutical aids to support them with smoking cessation would indicate that healthcare professionals had played a part in encouraging them to give up smoking. Furthermore, advice and support from GPs or practice nurses may have laid the foundations for the patients to make the decision to stop when the patient felt it was the right time for them to do so.

In addition to the part played by cigarette smoking, there are some examples of recent literature that have explored the role that air pollution plays in causing, or exacerbating, the symptoms of COPD (Andersen et al., 2011; Ko & Hui, 2012). In this study however, only Alison spoke about how she was affected by air pollution and how she, and her friends with similar respiratory conditions, could no longer go out in the good weather during the summer months because of the detrimental effect of the pollen. In order to avoid attacks of breathlessness, this participant had become virtually a prisoner in her own home, unable to go outside because of the effects of air pollution or pollen. This indicated a significant reduction in the quality of life of someone who had talked about how much she used to enjoy going out with her friends. In a similar way to those who avoid exercise, people whose COPD is affected

by air pollution may avoid outdoor activities, or social gatherings in order to reduce their risk of exacerbations of their condition. However, although exercise-induced breathlessness may be limited by appropriate exercise and breathing techniques, helping those whose breathlessness can be induced, or perceived to be induced, by air pollution may be a more difficult challenge for HCPs.

The participants' experiences of the symptoms of COPD occupied a large part of their accounts in most cases. Breathlessness and chest infections were the two manifestations of the illness that were most frequently discussed. In contrast to the findings of Borge et al. (2011), pain was not specified as being one of the main symptoms for the participants in this study. There was a great deal of variation in the frequency of acute exacerbations, ranging from Bruce who, despite being diagnosed with severe COPD, had only experienced two exacerbations, neither of which required hospitalisation, to David who reported that he had sent for an ambulance sixteen times in the previous year and had ten or eleven admissions.

Clive and David spoke in detail about their experiences of acute respiratory illness. They described the fear they felt in these situations and their feelings of relief when they received emergency medical treatment. For several of the participants (Alison, Clive, David and Harriet in particular) spoke about the importance of prompt medical attention in times of crisis and this was something that people in the study valued in terms of meeting their needs. Existing literature has examined the experiences of COPD patients and healthcare professionals in terms of routine care (Yen et al., 2010). However, for the participants in the present study, there was a great deal more emphasis on the importance of prompt emergency care, either by paramedics (Clive, David) or from GPs (Elsie, Florence, and Harriet). It is possible that patients with long-term conditions accept that their illness means that they will need medical attention from time to time and therefore are reliant upon being able to receive this at the time they need it. However, if their condition is stable between these occasions and they are happy to take regular medication, visits to HCPs for routine checks may be perceived as intrusive and an unnecessary reminder of their ill-health. Other reasons for a lack of enthusiasm for routine appointments could be that they felt they were taking up the doctor or nurses time, or that the HCPs were carrying out a

tick-box exercise with no opportunity for the patient to discuss their own, individual needs.

All the participants in the COPD group of the study spoke, to some degree, about comorbidities. Some participants reported comorbidities that may or may not be related to COPD such as David who had an underactive thyroid, high blood pressure, angina, excessive fluid, anxiety, depression and took heart medication as well because of the effect of the COPD on its function. Elsie also talked about experiencing anxiety and panic attacks. Although these conditions had predated the diagnosis of COPD, Elsie spoke about how they interacted with her episodes of breathlessness, in a way corresponding to that described by Livermore et al. (2010).

Alison reported symptoms including acid reflux and thinning of the skin, over and above that which would be expected at sixty-five years of age, which they reported had been caused by the medication taken for their COPD. This meant that they had to take further medication to counteract these side effects along with medication to prevent bone density reduction that may arise as a result of long-term steroid therapy. This multiplicity of symptoms arising in COPD patients requires the type of care that is able to consider the patient's condition as a whole rather than as a set of different problems. However, Bower et al. (2011) found limited evidence of service organization designed to meet the psychosocial needs of those with multimorbidity, in that the present healthcare system is designed to treat individual conditions and the primary care system of reviews is conducted according to the treatment of separate long-term conditions. One solution to this situation would be the provision of "one-stop" clinics where people with long-term conditions, such as COPD, are able to receive treatment and support for their physical and psychosocial needs. This could involve multidisciplinary teams working together in one centre. In addition to making access to different types of care more easily available for patients, this could reduce the need for multiple appointments and therefore ease the financial burden on patients as well as the financial and administrative burden on the present healthcare system. The creation and organisation of such centres would require a radical changes in the present system of NHS patient care but a member of the North Manchester CCG who spoke at a meeting of one of the Breathe Easy groups which I

attended, reported that three such clinics had been opened in the area. This news was warmly received by the group and could form the basis of future care.

6.2 Discussion - experience of the healthcare system theme

Experience of the healthcare system is a theme that was understandably discussed in every interview with the COPD group. Basic themes within this organising theme were primary care, secondary care (with three outlying themes of diagnosis, starting smoking, and patient representative), emergency care and pulmonary rehabilitation. All participants volunteered their accounts of primary and/or secondary care in response to questions about their treatment for COPD. Again, these experiences were specific to each individual although there was a prevailing theme of needing to access urgent medical help in times of emergency. Their descriptions also differed according to whether they received the majority of their care from the GP surgery or attended hospital on a regular basis.

The majority of the sample were happy with the care they received from their GP surgery although Alison said that she went to the GP for other medical problems but felt that they knew little about COPD. Alison therefore preferred to attend hospital for care related to her COPD. With regards to the theme of primary care, very little appreciation was shown by any of the participants in the study towards the regular routine reviews offered by GP practices as part of the changes that came about after the introduction of the Quality and Outcomes Framework (QOF) (Department of Health, 2003) into GP practices in 2004. Participants such as Florence and George had delayed making the relevant appointments because of other non-medical commitments and others referred to these consultations in terms of being checked out or having "*just routine*" checks. Introduction of these routine reviews ensured that every patient with a particular condition, such as COPD, is monitored on a regular basis. Recall systems are in place in GP practices and attendance at these review appointments should give the individual patient reassurance if their condition is stable and an opportunity to be given a change in medication, or further investigation, if the routine tests indicate that this is required. In addition, advice about self-management of the disease can be given with a view to giving the patient more control over the progress of their COPD and an improved knowledge of when

and how to seek emergency help where necessary. The outcomes of this system are designed to be beneficial for the patients and cost-effective for the NHS, in terms of a reduction in both inappropriate requests for emergency care and hospital in-patient stays due to exacerbations of COPD, which could have been avoided by careful monitoring and timely intervention. In addition, GP practices benefit financially by fulfilling the requirements of QOF regarding the monitoring of patients with long-term conditions. This financial benefit may, in turn, be used to improve services in primary care.

Although most of the participants in the study regarded routine reviews with the nurse as inflexible, Florence did say that she felt she could talk to their practice nurse about anything else that was concerning them. This is in contrast to the findings of Chew-Graham et al. (2013) who found that patients with long-term conditions felt unable to raise matters of emotional or social concern in routine reviews. It should be noted, however, that Florence had previously been employed at the Health Centre where she was registered as a patient and this may have some bearing on the relationship she had with her GP and practice nurse. This former working relationship was relevant when discussing whether she was able to talk to the practice nurse about problems that were not directly related to the physical checks being carried out, or the fact that she was able to call the GP for a prescription, when she felt she had an acute chest infection.

Overall, the sample in this study were happy with the care they received from the present healthcare system. No one in the study said that they had sought private healthcare. This may be due to their financial circumstances although Elsie reported that she had no concerns about money and expressed her satisfaction with the NHS care she received. However, some had taken other steps to ensure that they were getting the care they felt was best for them. For example, in terms of the theme of secondary care, Alison and David reported that they have both changed from the local hospital to one that was situated a greater distance away but has, in their view, a more highly regarded respiratory department. Both of these participants were pleased with the move and felt they were getting a better standard of care. However, others in the group were satisfied with their treatment at the local hospital. Elsie felt

that her condition had improved with the new medication regime she had been given at the hospital and rated the hospital as “*amazing*” (295). Harriet was also satisfied with six-monthly visits to the hospital and with the care she received there as an inpatient. She commented that she had been on the same medication regime for many years and appeared satisfied that, despite her one inpatient stay, this combination of check-ups and medication were keeping her COPD stable.

There were three accounts of experiences within the secondary healthcare system that were not common to other members of the COPD group but were, nonetheless, noteworthy as examples of events that were interpreted as being an important part of these individual participants’ lived experience. Clive recounted how he had discovered his diagnosis of COPD by accident when he saw it on his record sheet during a period as a hospital in-patient. Unaware of the implications of this diagnosis, Clive continued to smoke and was not given any information about the illness or medication until he saw his own GP some time later. In this participant’s experience, he found that his GP practice was a good source of information unlike the participants in the study by Chew-Graham et al (2013) who left their practice nurse consultations with unmet informational needs.

The second individual narrative of interest concerning secondary healthcare came from Florence who explained how she started to smoke when she was in hospital having given birth to her daughter over thirty years ago. Her narrative is a good indication of society’s attitude to smoking at a time when the majority of participants in this study would have been smokers, or starting to smoke. This would have been when smoking was still regarded as a positive experience that increased attraction and helped to relieve stress. The dangers of smoking were either less well known or unreported and there may have been considerable peer pressure acting upon people such as Florence who was encouraged to smoke by other new mothers who were in the ward at the time. Although this happened many years ago, it has had long-term consequences for her health. It therefore helps to illustrate the lack of awareness of the dangers of smoking that existed in that era and the context in which people who have COPD today, may have started to smoke. An awareness and acknowledgement of this context may be helpful when advising patients about smoking cessation.

Thirdly, Bruce spoke about his experiences of working on a Patient Representative Group (PRG) at the local hospital. Unfortunately, he felt that his views were not being taken into consideration and this was causing him to experience frustration, anger and disappointment. During the interview, Bruce indicated that, in his opinion, the hospital authorities were not taking the experiences and views of COPD patients into account. Although this experience was unique to one individual participant in the COPD group of the study, Bruce was acting as a representative of this patient group, and therefore his perception that some of the needs of COPD patients were not being met in secondary care, is something that may need to be addressed. The replacement of Primary Care Trusts (PCTs) by Clinical Commissioning Groups (CCGs) following the 2012 Health and Social Care Act allows for input from members of the public in the NHS decision-making process at a local level. However, whether this will prove to be a positive step towards increased patient involvement or will be regarded as a token gesture in the way that Bruce perceived his own contribution, will depend upon the structure and dynamics of the individual CCGs. Bruce himself may have had unrealistic expectations of his influence on the hospital authorities. Although the PRG is invited to submit their views and recommendations, it is the hospital or CCG that will ultimately make decisions based on input from a number of sources and reflecting the various medical, financial and ethical influences acting upon them. It may be advantageous for the hospital to manage the expectations of their patient representatives, in an induction or training session, in order to clearly establish what the patient can expect from their involvement in terms of effecting changes to the hospital's organisation and practice.

Emergency care was a theme that emerged from a number of interviews. As described earlier in this chapter, participants in this study regarded prompt medical assistance in an emergency situation as a healthcare priority and no one in the study referred to this in terms of being an unmet need. In terms of the aims of the study, the need for emergency medical treatment may be regarded as a perceived need, in that in some cases, the outcome may be what the patient, or their relative who made the decision to seek emergency medical help, may have anticipated. For example, David, who recalled that he had phoned for an ambulance many times in the previous

year and while some of these incidents resulted in a hospital admission, in other cases, he was sent home after medical advice, which could possibly have been obtained from another source. However, on one occasion, the decision to call an emergency ambulance was reinforced by the paramedic who stated that David's condition could have proved fatal if they had delayed the call by fifteen minutes. This incident highlights the difficulties faced by COPD patients and their carers when faced with making the decision whether to seek emergency treatment.

Individuality was evident in their interpretation of what required emergency care in that some relied on the attendance of ambulance staff and paramedics (David) while others, Clive for example, were more likely to ring the COPD nurses for advice and some, such as Elsie, phoned their surgery or out-of-hours service for urgent care and Alison contacted their hospital respiratory department. Despite there appearing to be no common strategy for obtaining emergency care among the participants in the study, none of the interviewees said that they had trouble in contacting a healthcare professional when required.

Overall, therefore, regular hospital check-ups were appreciated and participants spoke of adopting changes in medication suggested by the consultants. A high level of respect for hospital consultants (or specialists) was evident from the data whereas some of the participants were critical of their GP care, regarding them as knowing little about their particular condition. To some extent, this is to be expected in terms of the way the healthcare system is structured, with GPs referring patients to specialists for their particular condition. The introduction of primary care monitoring and the increased emphasis on self-management for long-term conditions may be something that is difficult for older patients who have been treated in a certain way for many years, to appreciate. However, none of the participants talked of the value of regular checks at the GP surgery or of being encouraged to change behaviour as a result of routine primary care reviews. These findings reflect those of Hunter et al. (2014) who found that although healthcare practitioners are aware that some forms behaviour change can be beneficial for COPD patients, this was rarely brought up as a topic in consultations (Hunter et al., 2014). It is difficult to establish whether this can be regarded as an unmet psychosocial need in terms of the research question. It

could be argued that patients need to be told to give up smoking and take more exercise but there is no indication from the data in the present study that this form of advice would be perceived to be of value by the patients themselves. It can be argued that these routine reviews are designed to check breathing status and medication use and that practice nurses do not have sufficient appointment time or relevant training to deal with psychosocial problems. However, if this type of advice and support is of value to those patients who would benefit, it is possibly something that should be considered for inclusion in these consultations with a view to improving the overall health status of people with long-term conditions. This is especially important considering the known prevalence of anxiety and depression in this population.

One aspect of healthcare that was appreciated by several of the participants in the COPD group was pulmonary rehabilitation (PR). Of those who had attended a PR group, Alison, Bruce and Elsie reported it as a positive experience. These participants agreed with the findings of Lacasse et al. (2009) who reported that PR was beneficial in both improving exercise capacity and controlling progress of the disease. Bentsen et al (2010) also found that attending a course of PR resulted in improvements in both psychological and physical functioning and that this effect was greater in those with a higher baseline measure of self-efficacy. The present study did not include a measure of self-efficacy so no direct comparison can be made with these findings. However, Bruce was a well-informed individual who spoke at length about the measures he took to ensure that he kept himself healthy and he was particularly enthusiastic about the benefits of PR, despite (unlike most of the other participants) being critical of almost all other elements of the present UK healthcare system in other respects.

The joint statement of the American Thoracic Society (ATS) and European Respiratory Society (ERS) in 2013 stated that those with mild COPD could derive improvements in their symptoms, exercise tolerance and quality of life (QOL) in a similar way to those with more severe COPD (Spruit et al., 2013). However, Jacome and Marques (2014) in their review of the evidence concluded that there was insufficient evidence yet to support the extension of the PR programme to patients with mild COPD.

Amongst the other participants, Florence had not been asked to attend a PR course and felt that her COPD was not severe enough for her to benefit. Although GPs are aware of guidelines with regards to the referral of patients to PR, it is ultimately their decision as to whether they think a patient will benefit from this intervention. Participants in this study who worked as respiratory therapists in PR spoke about the need to make primary care HCPs more aware of the potential benefits of PR with the intention of increasing awareness and encouraging more patients to take advantage of the support it offers.

George said he could not be sure whether it had been beneficial but felt it was important to improve his overall fitness and Harriet did not wish to attend. Clive talked about how he had started a PR course some years ago but felt that the exercises were too easy. Clive also experienced problems with travel to the venue and coordinating the times of the meetings with the opportunity to be able to use the bus pass. This was in line with the findings of Keating et al. (2011) and Holland & Hill, (2011) who both stated that travel difficulties were found to prevent people from taking up places on, or continuing to attend, a course of PR. However, Clive added that, his condition had become much more severe since that time and said that he may have been complacent in feeling that PR would not be beneficial for him when he did have the opportunity to take part. According to the data from HCPs who work in PR, financial constraints make it difficult to offer the course to people on a regular basis. However, this may be something that could change with the introduction of CCGs and the opportunity to tailor services to the local community thereby targeting the prevention and treatment of diseases that are prevalent in a particular area.

Halding et al. (2010) concluded that the sense of belonging was an important factor in the benefits obtained from PR and this was reflected in the views of Alison who spoke enthusiastically about the social side of PR and how they had met new friends there. Spruit et al. (2013) in their joint statement of the American Thoracic Society (ATS) and the European Respiratory Society reported that symptoms of anxiety and depression could be alleviated by experiencing a programme of PR. However, although they talked of positive physical and social benefits of attending PR, none of

the participants in this study talked specifically about having experienced any improvement in symptoms of psychological ill health as a result of attending a programme. This may be as a result of my own inexperience in interview technique and it may have been possible to encourage participants to discuss this topic in more detail had I used more appropriate prompts when asking about their experiences of PR.

In terms of the research question, the data from the COPD group suggests that PR is regarded as being a positive contribution by the healthcare system, to the care of those with COPD and to meeting their psychosocial needs. Although specific psychosocial needs are not discussed in detail by most of the COPD group, the overall impression obtained from this part of the data is that the participants who have taken part in a course of PR have found it supportive in their everyday experiences of living with COPD. In addition, Elsie, who was attending a course of PR at the time of the interview, managed to attend despite suffering from panic attacks and being unable to leave the house alone. Furthermore, Elsie spoke about how PR gave her a sense of positivity that counteracted the prevailing sense of negativity around those with COPD. There will be a more detailed discussion about the content of the PR course and how it is designed to meet the needs of those who attend, in the later discussion of the study data from the healthcare professionals (HCP) group.

Although there was a general expression of positivity regarding PR emerging from the COPD group data, there was also evidence of the overall theme of individuality in that some spoke about the benefits of exercise (Bruce, George), Alison stressed the benefits of the social aspect of PR, whilst Elsie was appreciative of the feelings of positivity gained from attending. It would appear from the data therefore that patients have differing needs to be fulfilled by attending a course of PR and that they will also bring differing levels of self-efficacy, self-management and expectation to the baseline. Janssen and Engelberg (2010) in their review of the literature around the teaching of self- efficacy and self-management skills in PR concluded that it was important to tailor these educational programmes to the individual needs and abilities of COPD patients, in order for them to be most effective in achieving physical benefits and improving QOL. In addition, there will be some patients who do not wish

to be part of a group, whether it be in the form of PR or Breathe Easy. It may be advisable, therefore, to incorporate elements of the PR programme into one-to-one routine consultations for COPD patients who do not wish, or are unable, to attend a PR course.

6.3 Discussion - emotional reactions theme

The organising theme of emotional reactions was something that was spoken about directly by some (although not all) of the participants in the COPD group. Within this theme were the following two basic themes: anxiety and dyspnoea and mental health care. Examples of participants talking about their emotional reactions included Alison who spoke about being depressed and Clive who talked about the nurse trying to help him with panic when he was unable to go down the road because of breathlessness. David explained that he was taking medication for anxiety and depression and described in some detail the feelings of fear he had when he became acutely unwell and was struggling to breathe. George talked at length about the emotional reaction he had when he was first diagnosed and how he regarded emphysema as an emotive term because a member of the family had passed away at a comparatively young age due to the disease. George also said that he had changed and became very emotional now that he had COPD, although this may have been compounded by the diagnosis of a degenerative neurological condition in a close family member at the same time as George's diagnosis. George concluded this part of the interview by explaining that he felt men did not generally show enough emotion and therefore it was a good thing that this change had been brought about. The question of whether the participants' emotional needs were being met would appear to be a complex one, which will be discussed in more detail in the final chapter. However, there was an overall impression from the data that patients perceived that HCPs were doing what they could, in terms of prescribing medication or referring people to CBT. However this was accompanied by a low level of expectation among COPD patients with regards to the successful outcome of either of these forms of treatment.

More specifically, the interaction between breathlessness (dyspnoea) and emotional reactions was a topic discussed by some of the COPD group. Once again, the experience was described differently by individual participants. Clive explained how he could no longer walk up the road after experiencing a severe attack of breathlessness but later in the interview he spoke about experiencing panic in this particular situation. David's account of the fear he felt when experiencing breathlessness, and the accompanying physical symptoms due to lack of oxygen, was extremely vivid. In this case, David described the experience of his body shutting down and the fear of impending death. In contrast, Florence said that she had never panicked due to breathlessness as she had grown up with it and that her breathing had become better as she had got older, something she attributed to the fact that she did not dash around as much as she used to. This difference in experience may be explained by the variation in severity levels of the condition between individual participants. Severity levels were not recorded as a part of this study and could have provided useful additional information to support the exploration of individual experiences. Only Elsie actually described how breathlessness and panic interacted with each other reflecting the study by Hallas et al. (2012). In the case of Elsie, however, panic attacks had been present for many years before the diagnosis of COPD and therefore were not something that she had first experienced as a result of having the condition.

In terms of the research question, i.e. whether the healthcare system is meeting a need by providing education in breathing control and how to deal with attacks of dyspnoea with, or without, accompanying panic, none of the people in the study COPD group explicitly described being able to control their breathing as a result of being provided with such information or taught the relevant skills, although this was still in the context of overall satisfaction with the health service they received. The theme of individuality was again apparent in the way that each participant approached the challenge of breathlessness. Clive said that the nurse who had visited his home had taught him some breathing exercises but that they were difficult to put into practice and Clive had therefore found his own method of breathing to help during attacks of dyspnoea. Harriet also described her own way of dealing with

breathlessness by slowing down or stopping the activity she was engaged in at the time and, having not attended a course of PR or apparently being aware of having received any advice about exercise from her primary care healthcare professionals, regarded this as a good way to prevent breathlessness. None of the participants spoke about completing a successful course of cognitive behavioural therapy designed specifically to break the breathlessness and anxiety cycle, despite two people having been recruited from those attending a psychological therapies clinic that provided this particular intervention.

Some participants did, however, talk about receiving mental health care at a time in the past although none of them described it as being fully successful. Experiences of medication for anxiety or depression and of psychological therapies were, once again, different for each individual. Alison had refused medication for depression as they had had a bad experience of treatment after childbirth more than thirty years ago while David took medication for anxiety and depression and said that it sometimes helps. Both of these two participants had been offered CBT but Alison said that they felt it was more relevant to anxiety whereas they were depressed and David did not complete the course because he found the paperwork difficult to continue at a time when he was suffering a bereavement. Linda, the HCP in the present study who worked in psychological therapy explained that she used a modified CBT and adapted the therapy to the individual's needs. However, it was also evident from her interview that the therapy did require a certain amount of input in terms of record keeping and "homework" on the part of the patient. She did explain that some people found this to be a challenge and, for some, it was a barrier to taking part. According to Linda, older people sometimes had difficulty in adapting to an approach in which they were expected to make this type of contribution towards their own therapy. This may be due to their experience of healthcare where the "expert" acts upon a passive patient. It would also be of interest to explore whether there is any gender difference between those who are willing to actively take part in therapy and those who find the paperwork to be a barrier. Elsie did receive CBT at home for panic attacks and said that, although it was helpful for a while, the improvement was not sustained. Elsie continued by saying that her expectations of

success were not very high for the CBT as she had suffered from panic attacks for so many years that she could not expect them to go away readily. A further point of interest from the interview with Elsie was that she added that it was useful to be able to use her COPD as an excuse for not attending functions or doing something she did not want to do. It is possible, therefore, that there is some element of secondary gain for some patients in maintaining some element of disability due to the combination of COPD and panic attacks.

6.4 Discussion – loss theme

The theme of loss was encountered in every interview with the participants in the COPD group. The basic themes related to the organising theme of loss were loss of physical abilities, loss of role/status/identity (with an outlying theme of loss of education), loss of independence, loss of friends/social life and financial loss/gain.

All talked about some degree of loss of physical ability and some referred to the fact that activities of daily living (ADLs) took much longer to carry out due to breathlessness or the need to stop at intervals, during tasks such as getting washed and dressed in the morning (Alison, Clive), cooking (Alison, David) and housework (Harriet). Some of the COPD talked about having carers to help with personal care but, as reported by one of the HCP participants in this study, the limitations of the social care service mean that visits last only fifteen minutes which is far short of the two hours some COPD patients require to get up, washed, dressed, make and eat breakfast and take their medication in the morning. Hence, people with COPD often rely on family for practical help and support in meeting their psychosocial needs. As a consequence of an increasingly elderly population, sons or daughters of people with COPD who are taking on caring responsibilities are often older people themselves and may also have health problems. In addition, this generation of carers sometimes have multiple responsibilities in helping with childcare for grandchildren and meeting the care needs of partners with health difficulties. Some people with COPD said that, although they were still able to carry out their own personal care they were no longer able to do tasks such as the gardening (Elsie) or the cleaning

(David). Bruce, Florence and George spoke about not being able to carry out sporting activities they had enjoyed in the past. However, Bruce and George both adapted their exercise regimes to suit their condition in order to continue exercising. The ability to carry out ADLs appeared not to relate entirely to an individual's self-reported severity of COPD in that an individual such as Bruce, with a diagnosis of severe COPD but a positive mental attitude, was able to experience a self-reported good quality of life.

Participants in the COPD group spoke about their loss of role and identity and status and how they were no longer able to carry out tasks in the home. Alison also referred to how she had missed a great deal of education because of respiratory illness during the winter months of their childhood. Although this loss of education could not be attributed directly to having COPD, Alison appeared to regard her childhood ill health as something that developed into her present condition and, as such, was a part of their ongoing lived experience.

Changing roles was an important part of several of the COPD group's interview data. Bruce, for example, talked of his former role at work and gave the impression that he was highly regarded, despite his implication that he was not universally liked by his colleagues. It would appear that he had attempted to replace his lost identity as a respected employee in taking on roles on the committee of the local Breathe Easy group and on the PRG group at the hospital. However, these were both referred to as disappointing experiences and did not appear to replace the job satisfaction, or status, he had experienced in his employment. Others spoke of their changing role within the family, how they saw themselves as needing support from partners in times of acute illness and were no longer the main breadwinner in the relationship.

Such changes in role have an impact on identity and, in the case of this participant group it was almost universally a negative impact. Losses experienced by people with COPD in this study, such as a reduction in physical capabilities leading to a loss of independence, are also highlighted in the literature review conducted by Disler et al. (2014). In their review, Disler et al. (2014) also found that loss of hope and meaningless in life were present in some patients with advanced COPD. One of the participants in the present study, Clive, who had been told by the consultant that he

may be in the last twelve months of life, talked about being offered the possibility of transplantation. He stated that he was not hopeful of a good outcome, although it was apparent that he still retained some positivity in that he was planning to move to more suitable accommodation in the near future. This situation had brought about a change of identity for this particular interval in that he was no longer able to plan his future with any certainty and he was now in the situation of being someone who was required to accept the possibility of planning their end of life care. His priorities had been subjected to change and therefore he would have experienced a corresponding change in his psychosocial needs. In the conclusion to the review, Disler et al. (2014) stated that, despite improvements in medical treatment, people with advanced COPD still have unmet psychosocial needs and that future interventions aimed at reducing the symptom burden of this patient group should respond to their psychological and social needs. They conclude that further research should concentrate on addressing these needs. With reference to the research question, this study aims to follow on from the work of Disler et al. (2014) by exploring these needs in a small group of COPD patients and also examining the perceptions of healthcare professionals about meeting these needs, in order to gain a deeper understanding of the situation.

For others, such as Alison and David, a loss of social life was important. Alison talked about not being able to go to pubs or clubs with their friends and Alison and David both said that they had to severely reduce their social life because their walking was restricted. These problems can lead to social isolation. This was regarded in several different ways. Some participants had experienced an active social life and therefore continued to do this by joining Breathe Easy or by making friends at the PR group. In this way, they continued to join in with social activities but created new friendship groups with people who were experiencing similar challenge. Others made use of technology and chose to continue existing relationships by Skype or social media. Although those who reported that they no longer had a social life tended to be the most severely disabled by their COPD, this was not always the case. The situation regarding people's responses in terms of whether they adapted their social life or abandoned it completely were related to their personality or emotional state in

addition to their physical condition. Even so, this relationship was far from straightforward in that one participant reported that they were very depressed but continued to contact friends and family whereas another individual who was receiving treatment for depression reported that he had no social life at all now. This would appear to be an example of how the psychosocial needs of COPD patients are highly individual and require personalised interventions.

In financial terms, loss or gain was very much defined by personal perception rather than practicality. Alison, David and George all stated that they had to finish paid employment due to their COPD. However, despite concerns about potential financial loss, Alison said that they were financially better off in receipt of benefits and George was happy with the money he received when he took early retirement.

6.5 Discussion - locus of control theme

The final organising theme that was identified in the data from the COPD group was that of locus of control. This was related to the basic themes of: support (with outlying themes of the church and Breathe Easy), causes/triggers, progression/adjustment (including an outlying theme of planning for the future) and medication use (outlying theme of alternative therapies). Those with a higher internal locus of control believe that their health is within their own control whereas those with an external locus of control believe that what happens to them is a result of the actions of powerful others or of chance (Wallston et al., 1978). It has been shown in recent literature that older people with poor health are more likely to have an external locus of control and, in particular, they perceive that powerful others largely influence their health (Jacobs-Lawson et al., 2011). In addition, it has been stated that patients with complex medical problems and multimorbidity tend to exhibit a more external locus of control and regard themselves as having little control over their situation (Henninger et al., 2012). However, the participants in this study reflected the global theme of individuality in that, despite having a mean age of approximately seventy years and living with at least one long-term condition, their experiences would suggest personal differences in their perceived locus of control.

Participants in the COPD group had different ways of dealing with the consequences of their ill health, how much control they perceived they had over the situation and how much support they felt they needed. David took control of his situation by planning ahead for acute bouts of illness and ensuring that he had food and drink upstairs for times when he was unable to get downstairs for a few days. Although there were times when he needed external help, David continued to exhibit an internal locus of control by again taking control of the situation and planning ahead in registering with an Emergency Call Service. This implies that he perceived that he had the ability to affect the course of his illness by making whatever arrangements he deemed necessary to give him the best chance of recovery in an emergency. Two of the participants in the COPD group in the study, were regular attenders at Breathe Easy meetings. This would suggest that these particular individuals also had an internal locus of control with regard to their health as they had actively sought out and become active members of, a self-help group.

George also spoke about the support he gained from being a member of the church but, as well as referring to his religious beliefs frequently during the interview, he was still very active in trying to improve his own health by regular exercise with gym equipment at home and seeking help from both traditional healthcare sources and alternative remedies. George's data would appear to indicate that, while possibly having a strong external locus of control with regards to the cause of the illness, he expressed an internal locus of control in terms of taking steps to slow down the progression of the disease.

George's perception of the cause of his illness would appear to me to express an external locus of control in that he believed that illness was something under God's direction and therefore that the cause of his COPD was a decision made by a powerful other.

Although most of the COPD group acknowledged that COPD was generally caused by smoking, some stated that, although they had smoked, external influences had acted to trigger the development of COPD, possibly indicating a tendency towards an external locus of control and reduction in self-blame. Alison said that the healthcare professionals told her that she had not smoked enough for it to have caused

emphysema at the age of forty-eight and David said that, despite having smoked roll-ups for twenty years, the doctor had told them that the COPD had been triggered by an injury to the lung during a fall.

Despite having been diagnosed with severe COPD, Bruce showed an internal locus of control in saying that he had done his own research and had decided to take no medication at all. Bruce had concluded that his previous medication could have been detrimental to his health. However, other participants expressed a more external health locus of control, indicating that the future of their health was in the hands of powerful others i.e. the healthcare professionals who prescribed their medication. Harriet, for example, accepted the medication regime prescribed by the consultant without question and Ian confirmed his belief in the power of drugs. David talked about how his medication taken for COPD affected his other medical problems and how, in conjunction with healthcare professionals, he had reduced it to the lowest level at which he feels his condition is stable, thus indicating an apparent internal locus of control.

According to Schutzler and Witt (2014), those with a higher use of alternative medication showed higher internal locus of control. However, apart from Elsie whose son had taught her some meditation techniques, George was the only participant who talked about using alternative therapy in the form of a device that claimed to improve breathing by strengthening the muscles. How the participants were adjusting to the progression of the disease could be related to their locus of control. Florence and Harriet adapted by slowing down and carrying out less daily activities. In contrast, Bruce appeared to be able to adjust well to the changes that occur as the disease progresses, making only minor changes to his lifestyle and keeping his mind and body alert. Similarly, David indicated that they had an internal locus of control in that they were planning for the future and had taken control of adapting their home and travel arrangements to suit their requirements. However, others, such as Clive, spoke in a way that indicated that he found it more difficult to accept the progression of the illness and perceived that he had little control over his symptoms, thereby exhibiting a more external locus of control. This variation in perception may partly be accounted for by difference in severity of symptoms but other factors may also

play a part in their adjustment to living with COPD. For example, how long they have been living with the diagnosis of COPD, how far and how rapidly the disease has progressed will also contribute to their experience and ability to adjust.

In relation to the literature around locus of control, the work of Henninger et al. (2012) is relevant to the care of people such as those in the present study, in that they concluded that an awareness among healthcare professionals of patients' locus of control would inform the development of individual disease management strategies. This would be particularly relevant when working with patients who expressed an external locus of control.

6.6 Summary

To conclude this section of the discussion, the organising themes that emerged from the COPD group data were lifespan health, experience of the healthcare system, emotional reactions, loss and locus of control. Each of these themes was relevant, in some way, to all of the participants in the group although it was apparent that their experiences of the themes, as discussed above in this section of the chapter were different for each individual. Although all members of the COPD patient group in the study have the same long-term condition and are being treated by the UK National Health Service, their lived experiences, as recounted in the interviews, were unique to each participant. Each participant talked of having individual psychosocial needs and expressed their own unique responses to the care they received. The global theme of individuality therefore reflects these individual differences and, in terms of the research question for this study, is something that needs to be taken into consideration when aiming to meet the psychosocial needs of this patient group.

In the next chapter, I will discuss the themes that came out of the data from the healthcare professionals' group of participants. In the final chapter of the thesis, I will explore the similarities and differences between the data from this group and that obtained from the COPD patient group. In Chapter 8, the thesis will conclude with a discussion of these results in the context of the healthcare system and an exploration

of how the overall findings relate to the research question of how healthcare professionals are meeting the psychosocial needs of people with COPD.

CHAPTER 7 – DISCUSSION: HCP GROUP THEMES

This chapter will examine the organising themes that emerged out of the study data from the Healthcare Professionals (HCP) group. The themes will now be discussed in terms of their relationship to the literature, the overall theme of “Individuality” and the research question. The final chapter will link the results from both groups and explore the ways in which these two sets of experiences and perceptions agree and differ.

7.1 Discussion - working experience theme

The organising theme of working experience covers a large amount of the data obtained from the interviews with HCPs. The two basic themes associated with this theme were professional/training experiences and personal experiences.

The emphasis that HCPs put on their training during their interviews was unanticipated and therefore was not a topic covered in the literature review for the study. However, it was something that was talked about at length by several of the participants and, as such, became one of the basic themes that came out of the data from the HCP group. Their experiences of training emphasised the global theme of individuality in that each participant in the HCP group recounted different aspects of their training, which were memorable to them and had influenced their career. The participants in the HCP group talked about both their initial training, which had taken place for some as early as the 1980's (Simon), and their ongoing professional development. Pauline talked about training on the job while working as a respiratory nurse and receiving support from staff who were more experienced in the field. Tom also said that he had found that there were aspects of his job, such as palliative care, for which he had not received any formal training, but was a part of the package of care he provided for his patients. Linda talked about experiences in her training and early years of working as a nurse that she perceived to be distressing and how she had subsequently changed from general nursing to psychiatric nursing and eventually

into psychology in the hope of being able to work with patients in a holistic way. These experiences indicate a mismatch between training and expectations for some HCPs. It may be that some trainee nurses would expect to acquire certain specific skills through on the job training and this can be deemed acceptable if they are aware of this when undergoing their basic training. However, Linda talked about a more fundamental mismatch between her expectations and the reality of the situations she experienced while nursing in different areas. Whether these experiences were a result of unreasonable expectations on her part or inadequate patient care is a matter for conjecture. The outcome of Linda's particular nursing experiences led her to work in psychological therapy, which she described as rewarding and is an area of healthcare in which she feels she can work well and effectively.

Linda and Simon both felt that the psychosocial needs of patients were not being met in the early years of their working experience. However, Simon recalled that the concept of patient-centred care first came to prominence in the nineteen seventies and eighties. Simon added that those who are now involved with nurse training are more aware of the psychosocial needs of patients and that this has become a part of the present day training. By way of illustration, Simon explained about a new scheme to train nurses whereby they are able to take up a placement which involves three elements, working in an inpatient setting, out in the community and in outpatient clinics. Simon continued by saying that this continuity of support into the community is especially important when COPD patients are sent home with new technological equipment to use. In this account, it became apparent that Simon was also aware of the needs of relatives and carers who care for COPD patients in their homes. The study conducted by Al-Gamal (2014), found, not only that COPD patients with a high level of breathlessness experienced a higher level of psychological distress, but that their partners also reported that they experienced significant levels of anxiety and depression. This would support the need for awareness of the potential needs of carers of people with COPD. It would be advantageous, therefore, if carers could be accompany COPD patients to appointments or be made welcome at PR sessions and support group meetings. This would provide opportunities for carers to feel more included in the treatment of those they care for and to raise any questions or

concerns they have about their own health. The main barriers to this inclusion, particularly in terms of NHS appointments or PR, would be length of appointment time and the additional costs involved in training and employment of sufficient HCPs to cover the additional workload. However, this could prove cost effective if carers were to feel better supported and to become more knowledgeable and confident in their ability to care for those with COPD. Potential outcomes of this additional support for carers may include a reduced need for acute healthcare usage in COPD patients and carers themselves. Furthermore, support groups, such as Breathe Easy could become more involved in supporting carers thus relieving the NHS of some of the financial burden while also giving carers an opportunity to be involved in a more informal setting.

Some participants in the HCP group spoke about incidents in their working experience that had affected them personally. With respect to end of life care for those with COPD, research findings indicate that patients with non-cancer respiratory disease, such as COPD, have far less support from palliative care services than lung cancer patients have (Burt et al., 2010). In addition, patients in this situation often experience psychosocial distress and have unmet care needs (Janssen et al., 2010). Tom talked about how he found himself providing palliative care to COPD patients in the community, without having received specialist training for this aspect of his job, because he perceived that there was a need for this type of care. In terms of the research question for this study, it would appear from the data that HCPs perceive that they are working to meet the needs of COPD patients in the final stages of the disease, although there was no indication from this data set of specific training having been provided for this role.

With reference to the global theme of individuality, the professional and personal experiences of the HCPs were individual, both between disciplines and within professions. For example, physiotherapists who worked in PR experienced different challenges from those working in the community, nurses in hospital had experiences of life and death situations and emergency care whereas practice nurses were able to monitor the progress of the disease and administer routine care to their patients. Many COPD patients will experience the care of HCPs from different disciplines as

their illness progresses. They may have regular contact with practice nurses, GPs or respiratory consultants, attendance at a course of PR will involve input from physiotherapists and later in the course of the disease there may be occasions where they are cared for by hospital nurses and possibly also receive palliative care. The positive outcome of this arrangement is that they will benefit from the individual training and experiences of those working in the different fields. However, a healthcare system in which people with long-term conditions are cared for by multidisciplinary teams would ensure continuity of care, avoid the need for repetition of tests and information and ease the transition between one stage of the disease and the next. In order for this to be successful, however, HCPs from different disciplines would be required to share information and experiences so that they can work together towards achieving the best outcomes for their patients.

In 2012, NHS England published the “6 Cs”; Care, Compassion, Competence, Communication, Courage and Commitment as the core principles which all nursing staff should abide by (NHS England, 2012). The response from some members of the nursing profession has been that, although these are undoubtedly admirable qualities, they are already a part of good nursing care and do not need to be formalised in this way. However, the data from the HCP group in this study indicates that HCPs do not always abide by these principles. For example, participants have expressed a lack of empathy towards smokers or have perceived a lack of care in the work of colleagues. However, it may be that some professions, possibly pharmacists or administration staff, may feel that their role is of a more practical value and that these principles do not necessarily apply to them. The “6 Cs” are due to be extended to other HCPs. Adherence to these common core values would be a positive step in the implementation and smooth running of multidisciplinary teams.

7.2 Discussion – attitudes theme

These differences in experience, both professional and personal, were reflected in the organising theme of attitudes towards the three associated basic themes of: patients, treatment and the healthcare system.

One of the main illustrations of the global theme of individuality was the HCPs differing attitudes towards patients in relation to their experiences of breathlessness. Karen and Naomi talked about patients who were unable or unwilling to engage in exercise and were experiencing muscle wastage as a result of exercise avoidance. They were keen to involve such patients in PR in order for them to engage in appropriate exercise programmes.

Olive felt that patients who they had referred to PR did not want to attend because they had adjusted their lives to accommodate their breathlessness. However, Olive's acceptance of the situation contrasted with the attitude of Tom who perceived patients who were initially hostile to the idea of PR as a challenge. Tom saw part of his role as someone who could persuade those who were reluctant to attend that it would be beneficial to them. The experience of one of the COPD patients in this study reflects the opinion of HCPs who felt that some patients did not see the potential benefits of PR and he reflected later that he may have been mistaken at that time. Those people who had attended a full course of PR, without exception, were positive about its outcomes and it would appear that it is therefore a responsibility of HCPs to inform suitable patients and encourage them to attend.

Linda, however described some patients' problems with breathlessness from a different perspective. She explained how deconditioning could have a cognitive origin, arising from what she described as catastrophic misinterpretation of breathlessness symptoms, bringing about a response in the autonomic nervous system that, in turn, can eventually lead to behaviours such as anxiety, panic, or being afraid to exercise. Simon also talked in terms of the fear experienced by people with attacks of breathlessness and Tom recognized the psychological effects of the symptoms of COPD. HCPs whose attitudes towards their patients involves recognition of the potential interaction between physical and psychological effects of COPD are in a better position to open a discussion about emotional issues with their patients. Where appropriate, suitable interventions can be suggested, whether this may be PR to help with breathing control or psychological therapy.

Other examples of attitudes towards patients expressed by the HCPs as annoyance or frustration at lack of adherence to intervention what they are saying, but these

particular HCPs did not talk about there being a need to frame the information in a way that their patients would be capable of understanding. These comments imply a lack of compliance on the part of the patient either by being unwilling to follow advice (as in the first example) or by not being correctly informed about their condition (as in the second example) and places the perceived blame with the patients. Mary explained that information about how COPD affects the body, use of medication and benefits of exercise were all topics that would be covered in a PR course. The implication of this statement was that they believed that patients had been given this information but refused to change their behaviour. Alternatively, it is possible that the information had been framed in a way that was difficult for some patients to comprehend or accept, or that others may have been experiencing difficulties with memory. In addition, not all COPD patients are able, or willing, to attend such a course and may therefore rely on GPs or practice nurses to provide them with an appropriate level of education about their condition, which is required for them to be able to make informed choices about their care.

Smoking cessation was an area where some HCPs indicated that they gave their patients enough information and support but that, ultimately, it was the patient's own decision whether to stop smoking. This attitude towards patients may be related to the findings of Hunter et al. (2014) who found that, although HCPs were aware that behaviour change, in terms of increased exercise and smoking cessation, can be beneficial for COPD patients, these were rarely introduced as topics in primary care consultations. They found that some HCPs perceived that promoting behaviour change, such as smoking cessation, may damage the doctor-patient relationship and yet not result in the required behaviour change (Hunter et al., 2014). More practically, restricted consultation times would provide less opportunity to discuss such matters in detail and, furthermore, some patients are unwilling to attend routine reviews as they perceive them to be of little value. In terms of the research question, this could be regarded as not meeting the patient's psychosocial need for support with smoking cessation. Alternatively, the HCPs who do approach the topic but not pursue it, may perceive that they are providing information and support at

that stage, so that the patient can be empowered to make their own decision to stop smoking when they feel ready to do so.

Linda suggested that some people did not take responsibility for their own healthcare because, historically, the medical profession had created a situation in which the professionals have wanted to be perceived to have the knowledge and expertise and patients are passive recipients of their care. Olive reinforced this perception when she spoke about how the majority of their COPD patients accepted what she told them without question. Olive added that she sometimes felt she had to stop being *“so nicey-nicey”* (324) in order to convince the patient to follow instructions if they were in danger of becoming seriously unwell, or even facing possible death. This would appear to be an example of nursing care that does not follow some elements of the “6 Cs” (NHS England, 2012). Firstly, effective, ongoing communication between nurse and patient throughout the process of care would avoid the need to change from being *“nicey-nicey”*. Secondly, whilst acknowledging that this cannot always be avoided, competence may inform a standard of disease monitoring that may reduce the need for a sudden deterioration in health. Finally, although there is an overall expression of caring in that the nurse is seeking the best outcome for the patient, a compassionate HCP would act to avoid any further distress to someone who may be in a situation of acute illness.

In relation to the global theme of individuality, it should be noted that despite some HCPs appearing frustrated or dismissive, there were several examples of empathy towards patients in the data from the HCP group in this study. Pauline spoke about forming relationships with patients who subsequently passed away and Ruth explained how she understood a patient’s fear when they were close to death. Ruth also explained how she was sometimes affected emotionally by the narratives of COPD patients, and continued by narrating how she tried to meet some of the simple psychosocial needs of such patients, such as bringing them a warm drink when they were in A&E, without friends or relatives, in the early hours of the morning. This gesture illustrates that good nursing care involves caring and compassion and a commitment to go beyond the basic practicalities of patient care. However, it would prove difficult for nursing staff, however committed and caring they may be, to

translate these principles into actions in a situation where a hospital may be under staffed and targets have to be achieved. The healthcare system therefore needs to be structured and organised in such a way that HCPs are able to have sufficient time to carry out this caring role and to demonstrate the “6 Cs” (NHS England, 2012) in practical ways.

The attitudes of HCPs towards treatment were also illustrative of the global theme of individuality. For example, their contrasting attitudes to the patients’ experience of breathlessness inform the treatment options delivered by the individual HCPs. Some, Karen and Tom who worked as respiratory physiotherapists for example, regarded exercise and education delivered at PR sessions to be the most effective intervention whereas others, such as Linda, employed a psychological therapy based on cognitive behavioural principles to treat her patients. James, felt that the primary care setting in which he worked gave excellent medical care for their COPD patients and referred to the treatment provided by the doctors and practice nurses as fantastic. In relation to the research question for this study, the data from the interviews would suggest that these HCPs are meeting the perceived needs of their patients in different ways, informed by their individual philosophies and experiences.

Simon’s experience was in the care of COPD patients in critical care situations and he felt that treatment had improved considerably in this area, largely due to new, less invasive ventilation techniques. Naomi and Ruth however stressed the importance of COPD patients being able to use their routine medication correctly and reported that this was now easier for them, thanks to research over recent years. However, the pharmaceutical treatment is one, albeit important, element in the treatment of COPD, which is a complex condition influenced by a number of medical and biopsychosocial influences.

Continuing with the discussion of the theme of attitude towards treatment as a whole, Linda talked of wanting to treat patients holistically and adopting a biopsychosocial approach to the care of people with long-term conditions, such as COPD. Tom also stressed the need to be flexible in the approach to treatment in order to accommodate the differing needs of individuals and the changes they experience in their health from day to day. The experiences of COPD patients discussed in

chapter 6 of this thesis reflect the interaction between physical symptoms, such as breathlessness, with psychological conditions, such as anxiety and depression. These symptoms may also lead to social problems including financial concerns due to having to take time off work or social isolation and loneliness. In addition, poor living conditions or pre-existing mental health concerns may affect the progression and treatment of COPD. It is important, therefore, that these interlinking elements are taken into consideration in the treatment of people with COPD.

These individual attitudes of HCPs towards treatment are applied in a larger context in their attitudes towards the healthcare system. For those working in primary care, the Quality and Outcomes Framework (QOF), introduced in 2004, led to changes in the care of people with COPD. The practice nurse reviews patients annually, usually, in order to monitor the progress of their condition. James referred to this as a robust recall system and talked about how QOF had improved care for people with COPD.

However, recent literature has described how the focus of these review appointments was found to be on the biomedical aspects of the illness i.e. those that were assessed in order to fulfil the requirements of QOF (Chew-Graham et al., 2013). Furthermore, some patients reported that other concerns were ignored by the practitioner and that they had left the consultation with unmet biomedical, informational and emotional needs (Chew-Graham et al., 2013). Similarly, in the present study, participants in the COPD group did not express views suggesting that they valued routine appointments in primary care or that these were consultations in which they felt able to discuss their social or emotional needs, if necessary. This would suggest that the psychosocial needs of this sample of COPD patients were not being met in the healthcare system. Olive acknowledged that some of the COPD patients who attended their primary care review clinics were depressed and expanded on this by saying that she recognized depression in patients either because they were not taking their medication or their records showed that they were being prescribed antidepressants. There was no indication from Olive that COPD patients were actively screened for anxiety and depression or that the annual review sessions were an opportunity to discuss emotional concerns.

On a broader scale, Karen and Tom both spoke about how treatment of COPD was not regarded as a priority in the healthcare system, in the way that heart disease and cancer are, and speculated that this was because it was an unglamorous illness. The unpleasant symptoms of COPD, which include persistent cough, with excess sputum production, that can in some cases lead to incontinence, contribute to a certain amount of stigma experienced by people with COPD. This stigma can also be experienced by HCPs who work with COPD patients as opposed to those with more highly publicised conditions such as cancer or heart disease. Respiratory physiotherapy, for example, may be regarded as a less attractive prospect for those in training than sports physiotherapy. In addition to public attitudes, financial restraints in the healthcare system were referred to in several of the HCP interviews and these will be discussed in more detail when looking at the barriers to patient care, later in this chapter.

7.3 Discussion - patient care theme

The final organising theme from the data obtained from the HCP group was that of patient care. This theme incorporated the six basic themes of existing medical care, other support, outcomes for patients, outcomes for the healthcare system, barriers to care and future of care.

The group spoke positively about the existing medical care they provided for their COPD patients but, between professions and even within disciplines, there were individual variations in their perceptions of what this patient care entailed and their approaches to carrying out this care.

Those who worked in primary care expressed the opinion that they were satisfied with the care they provided. James said that, in the Health Centre where he worked, the practice nurse carried out the routine care of their COPD patients and the GPs saw those who were acutely ill. He added that they very rarely sent COPD patients for hospital consultant care unless they had pneumonia, an additional respiratory disease or a comorbid heart condition. Similarly, Naomi and Olive spoke about how the majority of routine care for their COPD patients was carried out in their

respective GP practices. Olive added that good communication between the GPs and practice nurses in the practice enabled them to divide the work in a way that would make best use of their particular skills and experience. Although this distribution of workload between GP and practice nurse may be beneficial to the smooth running of primary care, patients in this study still tended to place more emphasis on their contact with the GP rather than their routine appointments with the nurse. In order to fulfil the requirements of the QOF, the training of practice nurses in chronic disease care has become an important element of GP practices and has resulted in an increase in competency and responsibility in the nursing role. However, there is a need to educate patients to seek the type of primary care that is most appropriate for their needs at a certain stage of their illness to avoid the situation in which the patient's first response is to contact the GP. This could prove to be a difficult task as many COPD patients are older people who may find it difficult to adapt to this more recent system of care.

Working out in the community, Tom talked about how he met the needs of their COPD patients by running a 'hospital at home' scheme and an early supported discharge scheme, designed to reduce hospital admissions and shorten the length of stay for those who needed to be admitted. Tom was also involved in working with a PR group and he spoke enthusiastically about the reduction of symptoms and increase in quality of life that many patients gained as a result of attending these courses. Karen and Linda also gave positive reports of their work at PR and how effective it was as an intervention. Potentially, a combination of attendance at a course of PR, with an early discharge and 'hospital at home' scheme, if inpatient care does become necessary for an exacerbation of COPD would reduce costs to the healthcare system. In addition, and arguably more importantly, people with COPD could be assisted to both self-manage their condition and also, if their condition deteriorates, they would be able to receive care in their own home wherever possible.

In contrast, Pauline spoke about the care their COPD patients receive as hospital inpatients. Here there was a comprehensive package of care in place including referrals to a physiotherapist, occupational therapy and speech and language

therapy. In terms of the research question for this study, it would appear that this hospital is meeting the psychosocial needs of the patients but the system in place does not take into account the different needs of the individual patients. Wise (2015) states that medical care of hospital inpatients has improved in recent years but Disler et al. (2014) found, in their review of the literature, people with COPD still have ongoing unmet psychosocial needs. Packages of care, such as the one described by Pauline, have been introduced to address these issues but still require patients to attend multiple appointments at different clinics rather than receiving holistic care from one source. It may be that individualised care is not feasible in the secondary care system, particularly in the area of acute inpatient care. In this situation, the primary requirement may be regarded as the most efficient use of the expertise and equipment available within the hospital environment, in order to ensure the best outcome for the patient at that time.

Another source of care and support for people with long-term conditions is the voluntary sector. In the case of COPD, much of this support comes from the Breathe Easy self-help groups that are affiliated to the British Lung Foundation. Most HCPs in this study who worked in hospital or primary care had limited knowledge of these groups to pass on to their patients. It is possible that the patients in the health centre where some HCPs work have no unmet psychosocial needs that could be met by the support of a self-help group, however greater awareness of the availability of this type of support would enable people to make informed choices about their care. Blickem et al. (2013) carried out a study in the North West of England to examine how people with long-term conditions could be put in touch with community support groups in their area. They suggested interventions should be individually tailored to people's psychosocial needs and be relevant to their everyday lives but they also acknowledged that this would take a shift in health provision away from individuals towards network support and social engagement (Blickem et al., 2013). Blickem et al.'s (2013) work highlights the individuality of people with long-term conditions. The concept of moving some aspects of care for people with COPD into the community is a complex one. Although it would be advantageous for a number of individuals who may benefit from this type of support, participants in this study placed a great deal

of trust in HCPs and it would be difficult for them to regard support from the voluntary sector as having a similar value. Those who I encountered during my contacts with the Breathe Easy group tended to perceive the support they found there as something additional, rather than integral to the care they received from the healthcare system. Additionally, there are people with long-term conditions who feel unable, by virtue of their ill-health, or who would find it difficult and uncomfortable to seek support in the community.

Another basic theme that emerged from the data in the HCP group was the theme of outcomes, or more specifically, outcomes for patients and outcomes for the healthcare system. In terms of outcomes for patients, Pauline and Simon agreed, as found by Wise (2015) that outcomes for COPD patients in hospital have improved over recent years and James believed that improved primary care, in terms of medication, regular reviews to monitor progress of the disease and health promotion had contributed to better outcomes for this patient group.

The HCPs who worked in PR were unanimous in reporting good outcomes for patients who had completed this course. The outcomes included physical benefits, such as an improvement from baseline in results of the six-minute walk test but also improvements in quality of life scores and scores on the HADS. Karen and Tom talked about how PR aims to treat the whole person, including their psychosocial needs, and not simply the disease. Recent literature has also supported the effectiveness of PR in terms of improving psychological functioning. In a study carried out by Bentsen et al. (2010) with COPD patients who attended a six-week outpatient course of PR in Norway, participants reported significantly improved psychological and social functioning after completion of the course. Bratas et al. (2012) reported that improvements in health related quality of life and psychological health after a course of PR had reduced after six months. Halting and Heggdal (2012) reported that there was a need for ongoing professional and peer support in the year following PR in order to maintain the benefits and to put the new skills people have learnt into practice in their everyday lives. HCPs in the present study spoke about follow-up courses for patients who had completed the PR course, such as reduced rates at local

gyms, although they were unsure as to how many people did continue with the exercise regimes they had learnt at PR.

Linda also reported good outcomes for COPD patients who had undergone psychological therapy for comorbid anxiety and depression. She talked about tailoring the therapy to suit individual needs and relating it to the lived experience of the patient. Improvements in physical measures, smoking cessation and reduction in medication use were also reported by Linda as outcomes from this type of intervention. In terms of patient satisfaction, Linda compared those who had benefitted from a course of psychological therapy with those who had relied on traditional medical treatments for their psychological conditions. This perception is in agreement with the findings of Chew-Graham et al. (2013) who found that some patients who had attended primary care reviews for their long-term condition reported that they had left the consultation with unmet emotional needs. Despite the evidence, discussed earlier, concerning the interaction between physical and psychological ill-health, it may, however, be that some patients still perceive them as separate conditions. They may feel, therefore that it is appropriate to seek the help of different HCPs, whom they regard as specialists in their field, rather than discuss emotional issues with their GP or practice nurse.

Healthcare finance is a major topic of concern, which is brought to the attention of the public and HCPs on a regular basis. Unsurprisingly therefore, outcomes for the healthcare system were discussed by the HCPs, mainly in terms of financial benefits. Those working in different disciplines explained how their particular contribution to healthcare benefitted both the patients and the healthcare system. For example, Karen and Tom talked about how attendance at PR reduces hospital admissions and shortens the number of days in hospital for those who are admitted with acute exacerbations of COPD thus improving patients' quality of life and reducing costs of inpatient care. Similarly, Tom explained how the work of the community COPD service helped to reduce hospital admissions. Ruth talked about the benefits of health promotion and Linda explained that, using psychological treatments could save substantial amounts of money spent on unsuccessful traditional treatments.

Financial constraints acting on the healthcare system in the UK are also important factors in the barriers to care, which participants in the HCP group talked about in their interviews. Tom felt that the community COPD team required more staff but that chronic care was less valued by those in authority than acute care. Karen expressed the view that financial restrictions meant that they were unable to offer the PR service over a greater area and therefore offer the service to more COPD patients.

There were, however, other barriers mentioned by the HCPs. Transport problems were cited as a barrier to care in that some COPD patients had to travel long distances to attend a PR group and travel could also be difficult due to ill health and financial concerns. Acute bouts of illness, particularly during the winter months, were referred to by several of the COPD patients in this study and one person talked about his fear of contracting a respiratory illness from others when attending group meetings. Although HCPs in the study report that it may be possible to attend a later course of PR if someone has been unable to attend some of the sessions due to illness, this may involve a few months waiting time, during which the patient will not be benefitting from the intervention. In terms of transport, many people with COPD are elderly, may have sight difficulties or other comorbidities and no longer drive. Cuts in financial support for public transport and 'Ring and Ride' services in particular, have detrimental effects on older people's ability to travel to suitable locations, particularly in bad weather. These difficulties are highlighted in recent literature. More than half those in a study by Keating et al. (2011) said that transport difficulties were a barrier to attending PR and Holland and Hill (2011), in their review of recent literature around PR, also found that transport difficulties were a barrier to attendance.

Other barriers to attendance at PR included lack of perceived benefit (Keating et al., 2011). This was reflected in the views of some HCPs in this study who rarely referred patients to PR, and by some patients who either said that they did not complete the course or that they would not attend if it were suggested to them. It was proposed that, in order to overcome these barriers, others who have had experience of the

programme could communicate the potential benefits of PR to others in a way they would relate to (Keating et al., 2011).

Olive cited poor communication between different sectors in the healthcare system as a barrier to care and Tom talked about issues in primary care such as under diagnosis of COPD and lack of availability of GP appointments. Linda however, perceives that the difficulties lie with the traditional biomedical model of healthcare and, in particular, that the training that doctors receive does not equip them to deal with psychological conditions. It may be argued that medical training should be completely separate from the training required for a psychologist and that the two are essentially different. However, bearing in mind that, as discussed earlier in this thesis, people with long-term conditions have a higher incidence of psychological comorbidities than the general public, it is important that hospital doctors and GPs have the background knowledge and experience to be able to recognise and identify the signs of emotional distress. Assuming that this is the case, there is the further concern that, having identified that there is a need for some form of psychological therapy, there may be a lack of suitable resources available to which the patient can be referred.

The final basic theme in the area of patient care is that of the future of care. This is a topic that will be discussed in more detail in the final chapter in this thesis which will explore the similarities and differences between the data from the COPD group and that obtained from the HCP group and how these findings may be used to address the research question for this study.

7.4 Summary

Although the outlook for the future expressed by the HCPs was generally optimistic, once again, individuality was the overarching theme of this part of the data. Karen, Mary and Tom looked forward to expanding the number of PR groups in the area and making them more accessible. Pauline and Tom talked about expanding COPD care in the community and Tom, in particular, felt that an integrated service covering both acute and long-term care was the way forward. Linda's vision for the future was one

of holistic care and she felt that this paradigm shift was already beginning to take place. Linda spoke enthusiastically when she said, *"I'm just hoping that it's going to sort of open that way so that we're going to be able to treat people instead of a collection of body parts...as a whole person"* (492).

Having now discussed the findings from both the COPD group, in Chapter 6, and the HCP group, in Chapter 7, the final chapter of this thesis will look in detail at how these two sets of findings agree and differ. This conclusion will provide a better understanding of the research question for the study: The lived experience of people with chronic obstructive pulmonary disease (COPD): How are health providers meeting their psychosocial needs?

CHAPTER 8 – CONCLUSION

The final chapter of the discussion aims to draw together the results of the data obtained from the COPD group of participants and that from the Healthcare Professionals' group. In order to explore the ways in which these two sets of experiences and perceptions agree and differ I will refer to the objectives of the study i.e.

1. To establish the extent to which the physical and emotional symptoms experienced by individuals with COPD affect their quality of life and ability to carry out their day-to-day activities.
2. To understand how the experiences of clinicians in treating people with COPD are related to the perceived needs expressed by the patients.

The thesis will conclude with a discussion of these results in the context of the healthcare system and an exploration of how the overall findings relate to the research question of how healthcare professionals are meeting the psychosocial needs of people with COPD. This discussion will include a section on the limitations of the study, a reflexive analysis and suggestions for future research.

The outcome of this discussion will therefore be a greater understanding of the research question i.e. **The lived experience of people with chronic obstructive pulmonary disease (COPD): How are health providers meeting their psychosocial needs?**

8.1 Summary of themes

This section of the discussion will begin with a brief summary of the themes that emerged from the analysis of the COPD group data. In relation to the first aim of the study, i.e. to establish the extent to which the physical and emotional symptoms experienced by individuals with COPD affect their quality of life and ability to carry

out their day-to-day activities, identification and exploration of these themes produces a better awareness of the lived experience of people with COPD.

A thematic network analysis of the data from the COPD group produced the following organising themes: lifespan health, experience of the healthcare system, emotional reactions, loss and locus of control and the global theme was that of individuality (Fig. 4.1, p.102). As discussed in the results chapter of this thesis, the participants in this group spoke at length about their symptoms and how these affected their lived experience in terms of their quality of life and ability to carry out their day-to-day activities. Lifespan health was an important theme for the participants and several people had strong opinions as to how their present health problems had been influenced by childhood episodes of ill health or family respiratory problems. As anticipated, feelings of loss, often as a direct result of the symptoms of COPD, were evident in many of the interviews and emotional reactions were also often related directly to these symptoms, for example, anxiety experienced with episodes of breathlessness and depression as a result of inability to continue an active social life.

Experience of the healthcare system was a theme relevant to every interview and locus of control was related to patients' use of this system. Of particular importance was the finding that, in the case of those in the COPD group who talked of their experiences of emergency care, their locus of control could be interpreted as changing when their illness reached a certain critical point, during exacerbations for example. From being in a position where they felt in control of their health they quickly became in need of professional help and were happy to let others take control. In terms of person-centred care, this could be described as the point where someone with COPD changed from being a person to being a patient and is an important part of the lived experience of several of the participants in this study.

In connection with this observation is the suggestion that HCPs may use the term person centred care when they mean patient centred care because their encounters are invariably with the person as a patient. My assertion therefore is that an increased awareness in HCPs, of this process of change in perception occurring in people when they attend for treatment, would be advantageous with regards to enabling the patient to return to a position where they can become a "person" again and continue

to self-manage their condition once the acute illness has been treated. This will be highly relevant with regards to current NHS policy regarding self-management in people with long-term conditions.

The global theme of individuality reflects the differences in findings within each of the organising themes. Loss, for example, was explained by some participants in terms of being unable to carry out their activities of daily living in the way they had previously been able to, for others it was a loss of social life, while some spoke about losing their role in the family or workplace. Emotional reactions were also expressed in different ways by individual participants. Some said they were depressed; others talked about panic in association with breathlessness, whilst fear of dying was something that arose for some at times of acute illness. Although all participants had experience of the healthcare system, these experiences were also highly individual. There was a significant variation in where people received the majority of their care, some rarely attending hospital but receiving care from the GP or practice nurse whilst others relying almost entirely on hospital care for their COPD with infrequent visits to their GP.

My perception of the data obtained from the HCP group is that it was not in such great depth as that obtained from the COPD group. With some exceptions, notably Linda, the data from the HCP group was more factual and, at times, it appeared that the participants were supportive of their own discipline whilst lacking in awareness or appreciation of alternative options for the treatment of COPD. However, the data was valuable in that it supported the data from the COPD group and enabled a comparison of the perceptions of the two group.

The thematic network produced for the HCP data (Fig.5.1, p.150) illustrates the following organising themes: working experience, attitudes and patient care. The global theme of individuality reflects the individual differences in the perceptions and experiences of the HCP participants in the study. Although all the participants in the HCP group were currently working with people with COPD in an NHS setting, or had past experience of such work, their narratives differed in several respects. The professions of those involved in the study included GP, practice nurse, hospital nurse, respiratory physiotherapist and psychological therapist. There were differences in

experience that could be accounted for by the particular discipline in which an individual worked. For example, some of those who worked in primary care had little experience of the work of pulmonary rehabilitation (PR) groups and those who worked in hospital caring for people who were acutely ill may have had limited experience of working in a community setting specialising in chronic care.

However, there were other differences in experience that were apparent, for example in their expressions of empathy (or lack of empathy) towards patients in specific situations. Lin and Bauer-Wu (2003) emphasised the importance of empathy, along with understanding and reassurance, in supporting the psychosocial needs of cancer patients and it would therefore be reasonable to suggest that this would also apply to patients with progressive, long-term conditions such as COPD.

As with the COPD group, the global theme of individuality reflected these individual differences in experiences and perceptions. Different healthcare professionals can therefore bring their particular strengths to the overall care of COPD patients but good communication between those working within different disciplines is essential to ensure continuity of care.

8.2 Similarities and mismatches between the data from the COPD group and the HCP group

With regards to the second aim of the study, exploring the similarities and mismatches between the two sets of data bring about an understanding of how the experiences of clinicians in treating people with COPD are related to the perceived needs expressed by the patients.

The data indicated that both groups were generally satisfied with the care they received or administered. However, some COPD patients were proactive in choosing the care they felt was best for them while others passively accepted the treatment plan directed by their GP or consultant. There were examples of two of the COPD group choosing a different hospital from the one they were originally attending and of some actively seeking out additional support from other agencies, such as Breathe

Easy. In contrast, others in the group were happy to accept the advice and medication regimes given to them by their GP or hospital consultant, without question. Few, if any, of the COPD group expressed any dissatisfaction with their medical treatment and those who had felt that things could be improved had taken action to change the situation. Only one of the COPD group talked about choosing not to follow the advice of his respiratory consultant by not taking any medication for his COPD after doing his own research into possible side effects.

Those in the HCP group all talked positively about the work they did. The clinicians and nurses working in primary care spoke about giving a good service in monitoring the progression of the disease and the HCPs who worked in hospitals spoke about improvements in technology that enabled patients with COPD to achieve better outcomes. Physiotherapists and nurses who worked in PR found the job very rewarding and said that they felt it was highly beneficial to the patients at little cost to the NHS and HCPs working in the community reported a reduction in hospital admissions, along with shorter hospital stays, due to their intervention.

The main difference in perception regarding the healthcare system that emerged from the two groups of data was in the importance they attached to different aspects of care. HCPs who worked in primary care stressed the value of recalling COPD patients for regular checks, a system set up in order to meet the requirements of the Quality and Outcomes Framework (QOF). However, the COPD patient group data would suggest that patients place more value on emergency care and the availability of urgent medical care in an acute situation, than on routine care. Those who expressed the highest regard for the NHS were those who had received emergency care when they were experiencing frightening, and potentially life-threatening, episodes of illness related to their COPD. With reference to the research question, it may be that patients do not feel that they need to have their psychosocial needs met by the healthcare system but place more emphasis on having their urgent physical needs met. However, several of the COPD group talked about the benefits they had received from attending a PR group. For some, the outcomes were measured as physical improvements in their health and improved quality of life whereas others showed appreciation of the social support they had experienced. In this respect, PR

is meeting the psychosocial needs of COPD patients although they may be needs that the patients had not previously perceived as being unmet.

The emphasis placed on acute care in the NHS and the system whereby different conditions are treated by separate clinical specialties may now be less relevant as the patient demographic changes towards an older population with complex long-term conditions and multimorbidities. Should the healthcare system therefore adapt to take into account the psychosocial needs of these patients in order to concentrate on improving quality of life in those whose illness cannot be successfully treated? To some extent, policy is in place in the form of the QOF. However, it is possible that some patients, especially those from that generation, regard the healthcare system as existing to care primarily for the physical aspects of ill health and may be unwilling to discuss psychosocial matters in a consultation (or with a researcher), even if it were possible to do so. This medical model of care has been the dominant model in the healthcare system in the UK for many years and some of the COPD group in the study have been patients in the NHS since its inception in 1946.

8.3 The global theme of individuality

The global theme of individuality for each of the two data sets has implications for healthcare. In terms of the patients, this would suggest that patient-centred care and individual care plans drawn up through a system of shared decision-making between clinician and patient could be the most appropriate way forward. However, people who have experienced the medical model of doctor as expert, throughout most of their lives may be unwilling to take on the role of sharing the responsibility for their own treatment. Should it therefore be the role of the HCP to educate and enable patients to make their own informed decisions about their healthcare? And if so, are patients able and willing to take that responsibility? For some the answer appeared to be 'yes'. This situation was apparent when some participants in the COPD group said that they had tried having help, in the form of patches or tablets, to enable them to quit smoking but that they had not worked, so they had achieved their goal of smoking cessation by themselves. This could be regarded not as the HCP having failed

to meet the patient's needs, but having succeeded in enabling the patient to make their own informed decision when they were ready to do so. This could indicate therefore a potential mismatch between what the patient expects the HCP to do for them and what the HCP sets out to achieve.

HCPs who worked in PR spoke at length about the benefits that patients derive from attending a course. The contents of the course include appropriate individually tailored exercise regimes, disease education, breathing control and a number of interventions designed to meet the psychosocial needs of the group. These include talks about topics such as travel, financial benefits and social service involvement, how to use medication correctly and the relationship between breathlessness and anxiety, with an opportunity to be assessed by the psychological therapist to establish whether they could benefit from cognitive behavioural-based therapy. Another important aspect of the work of PR that some of the COPD group talked about, is the social aspect. Those who gain support from being part of a social group may also be more inclined to seek out and attend a support group, in this case, Breathe Easy. Although pulmonary rehabilitation is usually run as a group intervention, exercises are specifically tailored to suit individual requirements. In addition, according to the information given by HCPs in this study, there are opportunities for patients to discuss their individual needs and problems with members of the PR team in a way in which they may be unable to in the formal atmosphere of a GP or hospital consultation.

8.4 Reflexivity

In this part of this chapter I will reflect upon my own experience of the past three years working towards a PhD, paying particular attention to the challenges I have encountered and what I have subsequently learned about COPD and about myself as a result of this experience.

My decision to embark on a PhD took several years to come to fruition. I returned to part-time study approximately fifteen years ago in an attempt to succeed academically where I had failed almost thirty years previously. I found my new

experience of university life absorbing and ultimately fulfilling. Having achieved my initial goal of obtaining a degree in psychology, I subsequently studied for a Masters degree by research and, in examining the relationship between personality and memory deficits; I discovered the potential of research as a way of exploring the experiences of individuals. My background of working as a receptionist in primary care, combined with my new-found enthusiasm for research led to a successful application for a post as a senior research assistant on a health research programme working with people with long-term conditions. The experiences I encountered whilst working on this study were invaluable and taught me how research can contribute to improving health outcomes. On a personal level, working with experienced researchers, academics and clinicians, in addition to having the privilege of meeting members of the public who gave up their time to support the research, provided me with the enthusiasm, knowledge and confidence I needed to continue my studies. Therefore, when the opportunity arose to apply for a studentship to study for a PhD at MMU in the field of health research I was in a position to make a successful application and to begin my own research study exploring the lived experience of people with COPD.

Although I had employed quantitative research methods in my Masters study and the major part of my employment had been concerned with quantitative research methods, my interest lay with people rather than processes and in understanding, not measuring, their experience of illness. My research proposal, therefore, was to carry out a qualitative study designed to explore the lived experience of people with COPD, and the experiences of healthcare professionals who care for them. However, during the first few weeks of my period of study it became apparent that the Director of Studies who had been assigned to oversee my work wished to direct me towards a quantitative piece of research, involving the validation of a new measure. I found it increasingly difficult to form a good working relationship in the circumstances but lacked the confidence to challenge the direction of this supervision. However, after some months, with the support of other academic and administrative staff, I was eventually able to request a change of supervision and embark on carrying out my initial research proposal. Having successfully resolved this issue, I subsequently,

however, found myself facing the challenge of delayed progress and the associated administrative work involved in changing the direction of my study back to what I had originally planned.

Having eventually resumed my studies as originally proposed, I carried out a literature search of relevant papers published during the previous five years and, as a consequence, was able to formulate my research question i.e. "The lived experience of people with chronic obstructive pulmonary disease (COPD): How are health providers meeting their psychosocial needs?". I then began to make informal contacts with COPD patients and healthcare professionals to establish connections with groups of people whose lives are affected by COPD, either as people with the condition or as those who work with them in a professional capacity. I began to attend the regular monthly meetings of the local Breathe Easy support group, meeting members and talking to them about their lives and about my proposed research. I also spoke informally to former professional colleagues in primary care and made contact with healthcare professionals working in PR and psychological therapy.

Before I could commence recruitment however, it was necessary to fulfil the requirements of the NHS North West Research Ethics Committee (REC) and to gain approval to carry out my research in a particular NHS area, from the Research and Development (R&D) department of the local research network. After completion of the relevant online forms, submission of supporting documents and attendance at the meeting of the REC, assurances were obtained. However, further permission was required from the R&D department acting for the local NHS sites where recruitment was to take place. A combination of lack of clarity in the system, mixed messages received from various sources involved in the process and an element of misunderstanding on my part led to a further delay of several weeks before recruitment could take place. However the matter was resolved with the support of the chair of the REC.

Once recruitment was underway there were further challenges to be overcome. Several members of the local Breathe Easy group were happy to take part in the study but some of these were living with respiratory conditions other than COPD and were

therefore unsuitable for the study. Recruitment proved to be difficult among those attending the PR group and a number of those attending the psychological therapy clinic, although initially interested in taking part, subsequently felt too unwell to take part in the interview. However, with support from a local GP, it was eventually possible to recruit a sufficient number of participants with COPD to take part in the study. It was also a difficult process to recruit healthcare professionals to the study. Although those who had initially shown an interest in the study and had given their support in the early stages, were happy to take part, it proved challenging to recruit further professionals who had no previous knowledge of the purpose of the research. It was particularly difficult to recruit GPs who, in addition to having a heavy workload, tended to ask their practice nurses to take part because they were the professionals who carried out the routine checks on COPD patients. Having contacted several GP practices without further success it was decided to approach academics employed in the Department of Health Professions at MMU who had experience of nursing people with COPD. This proved to be a positive step and a number of staff members were happy to support the research. Despite taking longer than anticipated, I found recruitment to be a rewarding process and I feel extremely appreciative of the people with COPD and the HCPs who gave up their time to support the study and to provide two rich sets of data.

Having some experience of data transcription, I was aware that this would be a time-consuming process but, in listening again to the interviews during the transcription, I was able to immerse myself in the data and felt that this was the first step in the analysis process. Although I chose to follow the prescriptive method of Thematic Network Analysis (Attride-Stirling, 2001), the early days of the data analysis were confusing. However, having then spent some weeks coding the data, the extraction of basic themes followed readily and, eventually, through further analysis, the development of the organising and global themes for each of the two data sets was achieved.

On reflection, while the findings of the study indicate that COPD is a debilitating condition, which adversely affects physical abilities and quality of life, and also that HCPs are confident that the care they provide is supportive, the overall theme of

individuality for each participant group came as a surprise and challenged my preconceptions. Prior to carrying out the interviews, I held the assumption that, to some extent, people with COPD would experience the same challenges and have similar perceptions regarding the care they received. I also anticipated that the HCPs would express a uniformly empathetic attitude towards their patients and a common desire to fulfil the psychosocial needs of those they cared for. I now appreciate that, despite experiencing the same condition, people with COPD lead very individual lives and that their lived experience of COPD and its treatment will vary according to a number of physical and psychosocial factors. Similarly, the perceptions and attitudes of HCPs differ considerably according to personality, experience and the pressures and expectations acting upon them in their professional and personal lives.

Arguably, the most difficult challenge I faced in writing up my thesis was that of letting my own voice be heard in the discussion. Despite repeated guidance and encouragement from my supervisory team throughout the PhD process, I still found it difficult to appreciate that my own views could be of any value and, consequently have been reluctant to commit my conclusions and recommendations to the written word. However, my own development over the last three years had led me to appreciate that my perceptions, conclusions and recommendations have been informed by the literature I have read, the input and feedback I have received from academic supervisors and fellow students and, most importantly, by the experiences and perceptions of those who have given their time as participants in the study. I have now come to appreciate that “my voice” is an expression of the input gained from these various sources and, as such, has value and therefore deserves to be heard.

8.5 Limitations of the study

One limitation of the study is that the participants who were recruited to the study were all actively involved in their own healthcare in that they regularly attended their GP practice, outpatient respiratory clinic, pulmonary rehabilitation or a Breathe Easy support group. These participants were therefore not representative of the whole

population of people in the UK who have COPD. This population will include people who have COPD but remain undiagnosed as well as those who are unable or unwilling to engage with the healthcare system.

The interview data obtained for the study gave the perceptions of COPD participants on only one occasion. A longitudinal study, exploring their lived experiences over several months as the disease progressed would have provided a richer data set. However, this was not possible due to the time constraints of the study.

In terms of the content of the interview data, being aware that the study involved data from HCPs, the COPD group may have concentrated on providing information about their perceptions of treatment rather than their emotional experiences of day-to-day life. In addition, they may have biased their views in support of their healthcare providers despite being reassured that their data would not be identifiable.

A further limitation is that, although some of the participants reported that they were at a particular level of COPD, no standardised measure of severity of COPD was used in the study. Inclusion of such a measure would have provided additional data to enable an exploration of whether the perceptions of the COPD group of participants, regarding their lived experience, were in any way related to the severity of their illness.

8.6 Final comments, recommendations and suggestions for future research

Psychosocial support involves the culturally sensitive provision of psychological, social and spiritual care (Hodgkinson, 2008). Legg (2011) talks about psychosocial care for cancer patients as being essential but something that can be overlooked in the day-to-day activities of the healthcare professional's role. Referring to cancer care, Legg (2011) expanded on this by adding that psychosocial care is important as it impacts on several aspects of patients' lives, including quality of life, physical, social, cognitive, spiritual, emotional and role functioning. Evidence of similar effects

due to psychosocial needs arising from their ill health can be seen in the themes that emerged from the people with COPD taking part in this study.

The question of whether healthcare professionals are meeting the psychosocial needs of COPD patients is a complex one. Firstly, is it to be assumed that the UK healthcare system should be meeting such needs or should it exist purely to treat the physical aspects of ill health? Furthermore, do patients and HCPs agree what the needs of the patient are? Do some patients expect only to have their physical needs met and are therefore uncomfortable about discussing personal matters in a healthcare consultation?

The overall theme of individuality would indicate that needs were specific to the individual but, within this context, there were some predominant issues of relevance to COPD patients that were reflected in the organising themes discussed above. This final section of the chapter will examine how COPD patients and healthcare professionals in this study perceive that these needs are being met and makes recommendations for the future.

8.6.1. The role of PR in meeting psychosocial needs

The healthcare professionals in this study who worked in PR spoke in some detail about how the programme met both the physical and psychosocial needs of COPD patients. They explained how the exercise programmes were designed to improve physical ability and decrease breathlessness and how the educational part of the programme supported psychosocial needs through information concerning topics such as anxiety and breathlessness, financial support, travel advice and medication. The social support as a result of being a member of a group of people with a similar condition was also outlined by the HCPs.

The theme of loss in the COPD group data is something that can potentially be addressed at PR. In the data from the participants in the COPD group, the theme of loss encompassed a wide range of challenges for the participants. Both physical and psychosocial needs arose from this theme. A loss of physical capability, for example,

is something that is addressed in PR where outcomes indicate that appropriate exercise regimes, tailored to individual patients, increase exercise tolerance and reduce breathlessness (Lacasse et al., 2009). In addition, PR has been found to play an important role in providing support through social interaction and this something that is reflected in the data from some members of the COPD group in this study (Halding et al., 2010). I would recommend, therefore, that PR is made available to all those COPD patients who feel that they would benefit. As suggested by HCPs in this study who work in PR, there should be an increased number of PR groups that are accessible to people who may have difficulty in travelling long distances and that they should be run at times when those who are still able to work would be able to attend. The reported benefits of the expansion of availability of PR would include better outcomes for patients, reduced cost to the NHS in terms of inpatient hospital stays and a reduction in sickness leave for those who are still in employment.

8.6.2 The role of psychological therapy in meeting psychosocial needs

Data from one of the HCPs in this study suggested strong support for the use of psychological therapy in meeting the psychosocial needs of COPD patients especially those who have comorbid anxiety or panic. It was reported by one of the participants in the HCP group that a course of individually tailored cognitive-based therapy has been shown to produce positive outcomes both emotionally and physically. An introduction to this particular type of therapy was presented at one of the educational sessions during the PR programme attended by participants in the study. Those attending the meeting were then given an opportunity to be assessed by the therapist if they felt it may be something that would help them. However, in the geographical area in which the study took place, limited opportunities were available for people to benefit from this particular therapy although the HCP who worked in this field reported that they were optimistic for future expansion and this would be a recommendation from this study.

8.6.3 Barriers to meeting the psychosocial needs of COPD patients

Although there is evidence for the benefits of PR, some participants in the study spoke about barriers to attending the courses. These included lack of initial information and encouragement from health professionals, travel difficulties and acute episodes of illness, which made regular attendance challenging.

In addition, a recent intervention has been trialled within the present primary healthcare system, in which COPD patients were given additional psychosocial support. However, there were barriers to its successful implementation. In a study designed to explore the effectiveness of additional support for patients with COPD in primary care, Langer et al. (2014) introduced two Liaison Health Workers (LHW) into general practices to assist the practice nurses with their care. The patients who received this intervention were overwhelmingly positive about the way in which the LHWs supported them with their psychosocial needs in a way that would not be possible for a practice nurse who would be constrained by time limitations and the requirements of QOF. However, the LHWs were not integrated into the practices by the practice team and, once their trial period of intervention was completed, they found that it was not possible to continue the intervention with the practice staff who were working within existing limitations in terms of time and training. It would appear therefore that, despite the reported benefits to the patients, the financial and administrative barriers suggest that this intervention is not a feasible proposition in its present form. However, with appropriate staff training and changes in the structure of NHS commissioning services to local clinical commissioning groups (CCGs), this may be an intervention that may be considered for introduction into primary care.

According to the data obtained from the HCP group in this study, the predominant barrier to psychological support for people with COPD and comorbid anxiety, depression or panic is the lack of availability of psychological therapists. Despite the introduction of the UK 'Improving access to psychological therapies' initiative in 2009, which is a national NHS programme to increase the availability of psychological services for patients with anxiety and depression, HCPs in this study reported that there was still a shortage of therapists available (Department of Health, 2009). One

participant talked of GPs prescribing antidepressants as a first line therapy despite being aware that psychological therapy may be a more appropriate treatment for COPD patients with comorbid emotional problems. An alternative explanation of the situation was expressed by a HCP who worked in psychological therapy and said that it was their perception that GPs were not trained to identify psychological problems in people with long-term conditions. It is recommended that the current undergraduate education of medical students includes sufficient holistic approaches that they can recognise and identify psychological conditions in people with long-term conditions and this should be stressed as an essential element of the postgraduate training of those who wish to become GPs. This will draw together the guidance from NICE, and the extension of the 6 Cs and benefit patients by directly recognising their individuality.

8.6.4 The role of the voluntary sector

It is possible that some patients prefer to attend a self-help group run by volunteers, such as Breathe Easy, to discuss their psychosocial needs. Data from this study would suggest that this is not the primary aim of the particular Breathe Easy group attended by these participants and that they preferred to enjoy the social side of the meetings rather than talk, or be educated about, the challenges of their illness. During my first visit to one of the Breathe Easy groups, I spoke to one member who said that the only speakers he did not enjoy (at the meetings) were the doctors who came from the hospital to speak to them. He said that this was because they used a lot of technical language and were difficult to follow. Despite initially being appreciative of the support they obtained from the group, the participants in the study who attended Breathe Easy on a regular basis had become unhappy with their group. These opinions, in conjunction with data from my own field notes, taken after attending these particular Breathe Easy group monthly meetings from April 2013 to August 2014, indicate that, despite the best efforts of those who work hard to keep the group thriving, this particular group may not be meeting the psychosocial needs of its members.

However, Breathe Easy groups are run individually by groups of volunteers and therefore will have different emphases. Having visited two different groups during the course of the study, it has been interesting to compare the structure and atmosphere of the two groups. The second group (there were no participants recruited to the study from this group) was far better attended and had a more positive atmosphere, despite the fact that many of the members were very unwell and had multimorbidities. This group also had a greater emphasis on its contacts with the local healthcare professionals who attended regularly to keep the members informed of the latest information regarding their care. This group was situated in an area of lower socio-economic status, which could indicate that the psychosocial needs of its members may differ from those in the group from which participants in this study were recruited. This again reflects the global theme of individuality found in the study and the perceived need for psychosocial support to be tailored to the specific needs of individuals or, in the case of Breathe Easy, to a particular group of individuals.

8.6.5 Conclusions

The findings of this study would indicate firstly that participants in both the COPD group and HCP group perceived that PR supports the psychosocial needs of people with COPD. However, the financial restrictions acting upon the present healthcare system limits the number of available courses and the amount of support that people are able to receive in the follow-up period after completion of such a course. Travel difficulties due to lack of suitable public transport was a barrier to this type of care for some participants in the study and acute ill health is also a problem as this can interrupt attendance. However, data from the HCP group of the study indicates that there is an increasing awareness of the benefits of PR in primary care health professionals, which is leading to increased motivation in the patients who are referred for this type of treatment.

Secondly, data from the HCP group indicates support for psychological therapy in meeting the psychosocial needs of COPD patients. However, lack of availability of

therapists is a barrier that needs to overcome and data from the COPD group would suggest that patients do not perceive this type of therapy to be something with lasting benefits.

Thirdly, it would appear from primary care professionals in this study that they had little awareness of the potential benefits of Breathe Easy as a support for the psychosocial needs of people with COPD. In addition, reports from the COPD group would suggest that there are difficulties in the running and maintenance of such groups. Therefore, questions that arise from the findings of this study around the contribution of the voluntary sector in meeting the psychosocial needs of COPD patients, include the following: In the present financial situation, should more be done to encourage the setting up and running of voluntary groups, such as Breathe Easy, to meet the needs of patients with long-term conditions? Should the organisation of individual groups be more uniform, with greater input from the British Lung Foundation (BLF)? Or, bearing in mind the theme of individuality, should they remain a unique reflection of the needs of their members and the social area in which they are situated? I would perceive it to be unlikely that government funding could be made available to increase the profile and running costs of voluntary groups such as Breathe Easy. It would therefore necessitate increased reliance on the support of the British Lung Foundation if the groups are to thrive and people are to be made more aware of the work they do. Unfortunately, in attending meetings of one Breathe Easy group, I was made aware of some difficulties surrounding the financial relationship between the BLF and the groups. The recommendation therefore is that this should be clarified in order for them to have a good working partnership. If this could be attained and the groups were better publicised in their local area, they could attract enthusiastic members who could work towards building a group that could meet the needs of the local people with COPD.

Finally, the data from this study indicates that the main difference in perceptions about whether the healthcare system is meeting the psychosocial needs of people with COPD concerns the differences between the value that patients place on routine care compared with that expressed by the healthcare professionals. Findings from the COPD group suggest that, despite the introduction of QOF into primary care and

the resulting system of monitoring for long-term conditions, patients still perceive good care in terms of the availability of acute care. This may be in the ease of getting an emergency GP appointment or the prompt care provided by paramedics and accident and emergency units in dealing with exacerbations of the condition. HCPs in the study however value and support the benefits of the present system of chronic disease monitoring in reducing the need for emergency care. In order to alleviate this mismatch in perceptions, it may be necessary for HCPs to incorporate more awareness of the psychosocial needs of patients into routine encounters so that patients will feel able to discuss these issues with their GP or practice nurse. In addition, better education for patients, possibly through greater availability of PR courses, should be provided in order for them to be able to self-manage their condition. HCPs who took part in this study were invariably supportive of their own discipline and its financial value. Further study into the cost effectiveness of various treatments for COPD, such as PR, early supported discharge, hospital at home, health promotion, routine reviews and psychological therapies would make a valuable contribution to the evidence surrounding the care of people with COPD.

8.6.6 Future research

In the light of the above findings, the following suggestions are made for future research. As the participants in this study were all established in the healthcare system and therefore actively seeking support for their condition, future research would be enhanced by the recruitment of a greater number of people with COPD into studies exploring their perceptions of care. For example, the inclusion of those who would not normally engage with the healthcare system would provide a richer data set and would produce a broader picture of the situation. An exploration of the experiences of healthcare workers who are involved in the care of hard to reach COPD patients such as the homeless and those who experience alcohol or drug abuse problems would provide an insight into the psychosocial needs of those who do not actively engage with the healthcare system and into the challenges experienced in providing that care.

Furthermore, the involvement of younger, newly diagnosed, individuals, would provide an indication of the kind of interventions that are perceived to be required in the early stages of the condition. In addition, including participants who cover a broad age range would enable researchers to compare the perceived needs of those in the early stages of COPD with those who are experiencing more severe symptoms in the later stages of the disease. This would, however, require careful attention to the ethical issues surrounding the care of those in the final months of life.

In addition, a longitudinal study exploring the psychosocial needs of a cohort of newly diagnosed COPD patients could be carried out. This would enable researchers to add to the existing knowledge in this subject by observing the changes in perceptions of the lived experience of a group of people with COPD as their condition progresses. For example, comparison could be carried out between those who engage with healthcare at an early stage with those who prefer to wait until they perceive they have reached a stage where there is a need for intervention. For example, it is possible that early intervention, in terms of education about exercise and breathing control, correct use of inhalers and smoking cessation support may reduce the need for psychosocial support in the later stages of the condition.

As the present study took place in a small urban area of north-west England, it would be of interest to explore the perceptions of people with COPD covering a wider geographical area. This could include rural areas where there may be problems such as availability of transport or areas with a history of mining or heavy industry. The involvement of both patients and HCPs, using telephone or Skype to obtain data in order to overcome methodological challenges, would result in a greater depth of knowledge regarding the healthcare situation in areas that include a range of social circumstances.

In conclusion, having explored and discussed the data from both the COPD group and the HCP group of participants, it is apparent from the findings of this study that meeting the psychosocial needs of people with COPD is not perceived by the patient to be the most important aspect of their healthcare, particularly in circumstances where acute or urgent medical care is required. A dual situation arises in which the ongoing routine care which is offered to the person may be unappreciated, or even

ignored, as they wish to continue with their everyday living, without being reminded of their ill-health but, in a time of acute illness, they perceive themselves as patients in need of medical care.

It is important, therefore, that HCPs are aware of this potential change in people with COPD, between perceiving themselves as a “person” at times when they are well and a “patient” when urgent care is required. Despite some exceptions, for example practice nurses who see those people who do regularly attend routine reviews, HCPs most frequently encounter people with COPD as patients and therefore may be unaware of the need to support the patient in their attempts to restore this perception of being a person again. This support may indeed involve engaging people with COPD with the concepts of ongoing care and helping them to appreciate the potential value of self-management.

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APPENDIX 1 – COPD patient letter of introduction (V2)



**Manchester
Metropolitan
University**

Manchester Metropolitan University
FACULTY OF HEALTH, PSYCHOLOGY AND SOCIAL CARE

Date

Patient and professional perspectives on living with COPD

Elizabeth Gaskell Building
Hathersage Road
Manchester
M13 0JA United Kingdom

Dear Sir/Madam

I am a PhD student carrying out research in the Department of Health Professions at Manchester Metropolitan University. My Director of Studies is Prof Jois Stansfield, and I am carrying out an interview study exploring the lived experiences of people with COPD. I will also be interviewing healthcare professionals who are currently, or have been in the past, involved with the treatment of people with COPD, in order to find out about their experiences of the management of this condition.

It would be extremely helpful if you, as someone who has been diagnosed with COPD, would consider taking part in an audio recorded, interview, about your experiences of living with this condition. The interview should take no longer than an hour and can be held at your home, or another venue, at a time to suit you. All data will be confidential, any data which could identify you, (for example, names of people or places), will be removed before the recording is transcribed and analysed.

If this is something you may like to do, please read the Patient Information Sheet which comes with this letter and let me, or know that you would be interested in taking part. I will be pleased to meet with you, at a time and location to suit you, and will then be able to provide further details about your involvement in the study.

If you would like any further information or have any questions about the study, please contact me at the university (address above) or by email at Jennifer.a.watson@stu.mmu.ac.uk

Kind Regards

APPENDIX 2 – HCP letter of introduction (V5)

Manchester Metropolitan University
FACULTY OF HEALTH, PSYCHOLOGY AND SOCIAL CARE



Date

Patient and professional perspectives on living with COPD

Dear Colleague,

Elizabeth Gaskell
Building
Hathersage Road
Manchester
M13 0JA United

I am a PhD student carrying out research in the Department of Health Professions at Manchester Metropolitan University. My Director of Studies is Prof Jois Stansfield, and I am carrying out a qualitative study exploring the lived experiences of people with COPD. I will also be interviewing healthcare professionals who are currently, or have been in the past, involved with the treatment of people with COPD, in order to find out about their experiences of the management of this condition.

It would be extremely helpful if you, as someone involved in the care of COPD patients, would consider taking part in an audio recorded, semi-structured interview, about your experiences of the management and treatment of the condition. The interview should take no longer than an hour and will be held at your place of work, at a time to suit you. All data will be confidential; any participant identifiable data will be removed before transcription and analysis.

If you are interested in taking part, I will be pleased to meet with you, at a time and location to suit you, and will be able to provide further details about your involvement in the study.

I will follow up this letter by email or telephone in approximately one week's time but if you would like any further information in the meantime, please contact me on Jennifer.a.watson@stu.mmu.ac.uk

Kind Regards

Jennifer Watson
(PhD Researcher)

APPENDIX 3 – COPD patient participant information sheet (V8)

Participant Information Sheet

Study Title: Patient and professional perspectives on living with COPD

Name of researcher: Jennifer Ann Watson

1. Invitation paragraph

You are being invited to take part in a research study.

Before you decide to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and talk to others about the study if you wish.

Please feel free to contact me (my contact details are given at the end of this information sheet) if you wish to ask any questions about the study before you make your decision.

2. What is the purpose of the study?

The study aims to find out how people with long-term lung conditions feel about their illness and the treatment they are getting. This will be done by carrying out individual interviews with people who consent to take part. Interviews will also take place with some healthcare professionals including GPs, nurses and physiotherapists involved in the care of people with respiratory illnesses.

3. Why have I been invited to take part?

You have been invited to take part because you have been diagnosed with a condition called Chronic Obstructive Pulmonary disease (COPD), which is a term that includes chronic bronchitis and emphysema.

4. Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and also be asked to sign a consent form, which you will be given a copy of. If you do decide to take part you are free to withdraw from the study at any time and without giving a reason.

5. What will happen to me if I take part?

You will be asked to take part in an interview conducted by me at a place and time to suit you. This will be audio-recorded. Your name will not be used and anything you say which may identify you will be removed from the recording. Direct quotations may be used in the results of the study but you will not be identified by name.

6. What are the possible advantages/disadvantages of taking part?

There will be no direct advantage to yourself if you take part but your input may help to improve the care of people with COPD.

There are no disadvantages to taking part in the study other than the time it will take for the interview. This should take no longer than one hour. If, however, you start to feel tired

or unwell during the interview or find any parts of the discussion about your health distressing in any way, you will be able to take a break for a time. You are free to withdraw from the study at any stage without giving a reason but it will not be possible to withdraw any data which has already been anonymised.

7. Will my taking part in the study be kept confidential?

Yes. Your data will be identified only by a code number and all data will be handled in accordance with the Data Protection Act 1998. Audio tapes will be destroyed, or digital recordings of interviews will be deleted, after they have been transcribed.

8. Complaints

If you have a concern about any aspect of this study, you can speak me and I will do my best to answer your questions [contact details below]. If you remain unhappy and wish to complain formally, you can do this by contacting Professor Carol Haigh, Manchester Metropolitan University at the address below.

9. Contact details:

Email: Jennifer.a.watson@stu.mmu.ac.uk

You can also write to me at:

Manchester Metropolitan University (MMU), Department of Health, Psychology and Social Care, School of Health Professions,
Elizabeth Gaskell Campus, Hathersage Road,
Manchester, M13 0JA

A leaflet summarising the results will be available to all participants at the end of the study

APPENDIX 4 – HCP participant information sheet (V2)

Participant Information Sheet (HCP)

Study Title: Patient and professional perspectives on living with COPD

Name of researcher: Jennifer Ann Watson

1. Invitation paragraph

You are being invited to take part in a research study.

Before you decide to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and talk to others about the study if you wish.

Please feel free to contact me (my contact details are given at the end of this information sheet) if you wish to ask any questions about the study before you make your decision.

2. What is the purpose of the study?

The study aims to explore the lived experience of people with COPD and the experiences of healthcare professionals who treat them. This will be done by carrying out individual interviews with people living with COPD, who consent to take part. Interviews will also take place with healthcare professionals, including GPs, nurses and physiotherapists who are involved in the care of people with COPD.

3. Why have I been invited to take part?

You have been invited to take part because you are, or have been, involved in the care and treatment of people with COPD.

4. Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and also be asked to sign a consent form, which you will be given a copy of. If you do decide to take part you are free to withdraw from the study at any time and without giving a reason.

5. What will happen to me if I take part?

You will be asked to take part in an interview conducted by me at your place of work at a time to suit you. This will be audio-recorded. Your name will not be used and anything you say which may identify you will be removed from the recording. Direct quotations may be used in the results of the study but you will not be identified by name. Audio tapes will be destroyed, or digital recordings of interviews will be deleted, after they have been transcribed.

6. What are the possible advantages/disadvantages of taking part?

There will be no direct advantage to yourself if you take part but your input may help to improve the care of people with COPD.

There are no disadvantages to taking part in the study other than the time it will take for the interview. This should take no longer than one hour. You are free to withdraw from the study at any stage without giving a reason but it will not be possible to withdraw any data which has already been anonymised.

7. Will my taking part in the study be kept confidential?

Yes. Your data will be identified only by a code number and all data will be handled in accordance with the Data Protection Act 1998.

8. Complaints

If you have a concern about any aspect of this study, you can speak me and I will do my best to answer your questions [contact details below]. If you remain unhappy and wish to complain formally, you can do this by contacting Professor Carol Haigh, Manchester Metropolitan University at the address below.

9. Contact details:

Email: Jennifer.a.watson@stu.mmu.ac.uk

You can also write to me at:

Manchester Metropolitan University (MMU), Department of Health, Psychology and Social Care, School of Health Professions,
Elizabeth Gaskell Campus, Hathersage Road,
Manchester, M13 0JA

A leaflet summarising the results will be available to all participants at the end of the study

APPENDIX 5 – Consent form (V7)

Participant Identification Number:

CONSENT FORM

Title of project: **Patient and professional perspectives on living with Chronic Obstructive Pulmonary Disease (COPD)**

Name of researcher: Jennifer Ann Watson

Please initial box

1. I confirm that I have read and understand the information sheet dated 13.11.2013 (version 8 for patients/version 2 for healthcare professionals) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that the interviews will be audio recorded. This is to allow for analysis of the data and to select quotations to illustrate the results. The audio recordings will only be used for this purpose.
3. I give my consent for this and for direct quotations to be used as long as all information is anonymised.
4. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
5. I understand that relevant sections of data collected during the study, may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
6. I agree to take part in the above study.

☐☐☐☐☐☐

Name of participant

Date

Signature

APPENDIX 6 – Interview topic guide (COPD patients) (V7)

Jennifer Ann Watson – PhD Study

Patient and Professional Perspectives on living with Chronic Obstructive Pulmonary Disease (COPD)

Interview Topic Guide (1) – Patients with COPD

NB You do not need to answer any question that you do not wish to answer

1. What is your life like now? Tell me about a day in your life?

Prompts: Are all days the same?

What sort of social activities are you involved in?

What about your family?

2. How do you feel about your life now?

Prompts: Has it changed over the last few years? Why/how?

Are you impeded in any way?

Employment status

3. Tell me about your COPD and how it affects you?

Prompts: Does it have any advantages?/ Does it have any disadvantages?

How do you deal with these? (medication, Breathe Easy, CBT, other)

Views on asking for help

4. How do you feel about the care you are offered for your COPD?

Prompts: Good or not? Why?

Is there anything that could make it better?

Exacerbations

5. Is there anything else you want to tell me about living with COPD?

APPENDIX 7 – Interview topic guide (HCPs) (V4)

Jennifer Ann Watson – PhD Study

Patient and professional perspectives on living with chronic obstructive pulmonary disease (COPD)

Interview Topic Guide (2) – Healthcare professionals (this guide was adapted according to data from patient interviews)

Topic	Areas	Prompts
Background:	Professional background	
	Contact with COPD	GP/practice nurses: More or fewer than other practices?
	Any specialist training	
COPD and comorbidities:	Screening for comorbidities	If so at what point? How? Where?
	Willingness of patients to discuss	Physical psychological
Treatment and support	Treatment offered	Any specialist services?
	Accessibility	
	Referrals to service/onward from service	By whom? To whom?